

Practice Guidelines for Consumer Directed Services and Supports



**SELF-DETERMINATION COMMITTEE
PRACTICE GUIDELINES INITIATIVE**

**A Report Submitted to the Missouri Department of Mental Health
Steering Committee for Practice Guidelines**

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EXECUTIVE SUMMARY



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I. Introduction

The purpose of this document is to present guidelines for incorporating choice, participation and purpose as core principles for services delivered or funded by the Missouri Department of Mental Health (DMH). These guidelines delineate common values and goals among the particular populations, communities and cultures served by the DMH, while also highlighting values and goals unique to these different stakeholders.

In creating this document, we recognize the variety of terms used to describe the concepts—self-determination, recovery, resilience, and others. Unfortunately, many of these terms, while acceptable to some stakeholder groups, are problematic to others. We view these terms as similar in intent and philosophy. After extensive debate, we have chosen to use the terms choice, participation and purpose to represent the commonalities in these constructs rather than use other existing terms with a greater likelihood of causing misunderstanding and divisiveness. The concepts in this document are not new. They are included in the core principles and values of all the major Professional Associations' codes of ethics and professional conduct.

A unifying vision drives this guideline: ***DMH consumers have a right to maximum opportunities for independence and self-growth. Achieving this vision requires embracing the values of choice, participation and purpose. Choice, participation and purpose are not unchanging principles; they evolve as the individual develops.***

II. Definition of Terms

Choice is a value for decision-making that emphasizes maximum opportunities for realistic and informed choice to the fullest extent of each individual's capacity for decision-making.

Participation involves a broad range of involvement with others. From participation in planning and choosing one's own services; to system planning and advocacy to community participation in the full range of opportunities one's home community offers.

Purpose is the mutual responsibility of the individual and DMH to work together to provide meaning, a sense of achievement, and self-direction to the greatest extent possible for the person receiving services. Further, purpose is not static, but grows and changes as the individual progresses.

III. Methods and Evidence

Evidence used in creating this document was identified from a number of sources. Information is weighted on the following basis:

- Values and definitions provided through the mission statement;
- Evidence from the research literature;
- Previous consensus statements and the DMH mission statement;

- A series of meetings with stakeholder groups;
- Presentations by guest speakers; and
- Consensus emerged in committee weighing these factors.

Relevant literature was initially provided as part of the charge to the writing team. This included previous work in this area completed by the DMH and other state and national level organizations. An initial search of the scientific literature was conducted using bibliographic searches of relevant databases for key words of “self determination” and “recovery.” Additional bibliographic information was included from team members with specific expertise, including resilience in youth and family participation. A second search of the literature examined available treatment for evidence related to choice, participation, and purpose for that treatment.

Committee members examined abstracts of the articles identified from this search and articles selected if any individual felt that the article either included empirically derived evidence (including quantitative, qualitative, or rigorous case studies) or included definitions or conceptual discussions potentially useful to the committee task. These full articles were then read by team members and incorporated into the document. A broad range of stakeholders provided input to early drafts.

The literature is notable for a nearly complete lack of large scale, well designed, empirical studies with adequate control groups to support the individual concepts or specific interventions supportive of the concepts. However, there is broad, consistent, and compelling expert consensus supporting the meaningfulness of the concepts and individual supports and interventions that facilitate their achievements. The majority of the interventions discussed are also supported by a few controlled studies and a large number of uncontrolled program outcome reports.

IV. Addressing the Fears

Because there were concerns expressed around these terms and their meanings for various subgroups, this document addressed what were termed “cross-connections.” Discussions in this section included:

- Concerns About Self-Determination As It Relates To Substance Abuse
- Concerns About Recovery As It Relates To Developmental Disabilities
- Families Concerns About Self Determination In Mental Illness
- Consumer Concerns About Recovery In Mental Illness
- Family Concerns About Self-Determination In Developmental Disability

V. Implementing the Constructs into Service

This section presented a number of initial, incremental recommendations. It is important to note that fluctuations in funding are opportunities to make changes toward a more efficient and effective system. Implementing choice, participation, and purpose should not be considered as an added expense, rather as an opportunity to provide better services and supports—which may

or may not impact costs. The remainder of this section detailed recommendations for some of these initial steps, and was driven by the following vision.

The system must focus on human beings, not their problems, through:

- Infusing a person-centered philosophy throughout DMH;
- Allocating and expending resources using a person-centered perspective rather than a provider-centered one;
- Creating the means by which the system and the consumer are mutually accountable;
- Focusing on providing services and supports aimed at maximizing life potential rather than “treating” disabilities and illness alone;
- Recognizing the partnership between the person and DMH necessary to achieving the realization of choice, participation, and purpose.

Specific recommendations are presented for various aspects of individual services. These include:

- Initial Contact
- Assessment/Intake
- Service/Treatment Planning
- Service/Treatment Delivery
- Outcomes

Specific recommendations are presented for system change. These include:

- Creation Of Standards Of Guardianship Documents Presented To Judges, Levels Of Guardianship, Alternatives
- Providers Need To Be Trained In Advocacy
- Creation Of System Monitoring Procedures
- Community Education

Finally, recommendations are presented for changes within each of the three divisions.

This document begins the change process. To measure subsequent change, it is necessary to closely compare the current practices to our vision of choice, participation and purpose. Methods used to complete this comparison need to be based in a person-centered approach. This would include examining: (a) barriers and facilitators of access, (b) provision of supports and services, (c) relationships between persons receiving services/supports and their providers, and (d) successes and failures within the system—all from the perspective of those receiving the services. Thus, the question is not “what is in the treatment/personal plan?” but rather “How is this perceived by the person?”

SECTION 1. OVERVIEW AND DEFINITION OF TERMS



SECTION 1. OVERVIEW AND DEFINITION OF TERMS

Introduction

The purpose of this document is to present guidelines for incorporating choice, participation and purpose as core principles for services delivered or funded by the Missouri Department of Mental Health (DMH). In developing this document, we are drawing information from a variety of resources:

- National trends toward increased consumer and/or family involvement,
- Published literature (evidence and personal narratives) related to these concepts,
- Ethical standards and values which focus on the individual first and foremost,
- Existing DMH documents, and
- Consensus from providers, consumers, and their families.

The purpose of these guidelines is to delineate common values and goals among the particular populations, communities, and cultures served by the DMH, while also highlighting values and goals unique to these different stakeholders. Movement toward choice, participation and purpose means different things to individuals with varying abilities and capacities. Nevertheless, many common values and goals exist.

In creating this document, we are driven by the belief that all DMH services should be:

- Consumer-directed
- Person-centered
- Capacity-building
- Evidence-based
- Family-focused
- Community-based
- Culturally respectful and competent

It is our contention that incorporating these beliefs into services has added benefit beyond humanizing practice. Ample evidence documents that increased involvement in community-based support and services is associated with substantial reductions in use of institutional services. Thus, services incorporating choice, participation and purpose should increase positive, meaningful, and effective participation without increasing overall costs. Simply, services based on choice, participation and purpose better engage DMH consumers and, therefore, are more effective.

In using the term *DMH consumers*, we are including persons coping with a variety of challenges within the services provided by the DMH, including adults, children, and adolescents, as well as parents, family members, and other caretakers of persons who are the direct recipients of DMH services.

The document will be structured into the following sections:

1. Vision statement, including definition of central concepts, populations, and terminology;
2. Evidence related to choice, participation and purpose from the literature;
3. Information previously developed by DMH and consumer organizations relevant to these concepts;

4. Recommendations for implementing these concepts across the DMH: Division of Alcohol and Drug Abuse; Division of Comprehensive Psychiatric Services; and Division of Mental Retardation/Developmental Disabilities.

In creating this document, we recognize the variety of terms used to describe these concepts—self-determination, recovery, resilience, and others. Unfortunately, many of these terms, while acceptable to some stakeholder groups, are problematic to others. We view these terms as similar in intent and philosophy. After ongoing debate, we have chosen to use the terms choice, participation and purpose to represent the commonalities in these constructs rather than use other existing terms with a greater likelihood of causing misunderstanding and divisiveness. In sections related to specific divisions in DMH, we will use the language most familiar to those populations and providers. Readers preferring other terms should feel free to substitute their favorite ones at will so long as they recognize and adopt the principles herein.

1A. Vision Statement

DMH consumers have a right to maximum opportunities for independence and self-growth. Achieving this vision requires embracing the values of choice, participation and purpose. Choice, participation and purpose are not unchanging principles; they evolve as the individual develops.

1B. Values and definitions

Choice

Choice is a value for decision-making that emphasizes maximum opportunities for realistic and informed choice to the fullest extent of each individual's capacity for decision-making.

Choice embraces the values of:

- Enhancing the possibilities for people to control their own lives and be self-reliant;
- Exercising the same rights as all persons, including making personal choices and experiencing consequences;
- Having the power to act in your own interest;
- Gaining competence and self-discipline by making choices and learning from them.

Choice is not:

- The same as unlimited freedom to make choices but represents a commitment to maximize opportunities for autonomy, self-direction, and the exercise of personal responsibility whenever and wherever possible.
- A promise of unlimited success, but a commitment to reaching for dreams without limitations imposed *solely* because someone else “knows better”, constrained by the consumer's own actions, abilities, and judgments.
- A concept that exists in a vacuum: the consumer reaches for this goal through a variety of supports, including family, peers, community, professionals, and the legal system.

Participation

Participation is involvement by the individual in a broad array of services that are identified and offered through a consensus process among the stakeholder groups. This includes minimally the individual receiving services and professionals from DMH, but should also include the family

wherever possible, and other systems where either mandated (e.g., the legal system or DFS) or requested by the person receiving services.

A. Participation happens when individuals:

- Feel truly heard
- Have hope
- Feel respected as a person
- Feel encouraged
- Feel self-confident
- Are motivated
- Desire to grow
- Are educated
- Are empowered
- Are actively involved
- Live without stereotypes or stigma

B. Participation happens when DMH and providers:

- Cultivate respect and trust between consumer and provider
- Truly listen
- Believe the person can achieve more
- See the person holistically, not just as a diagnosis
- Involve consumers on the state and regional levels in DMH advisory councils, committees, and work groups to incorporate their opinions on how to improve supports and services
- Set guidelines for how and when providers interact with consumers

Purpose

Purpose is the mutual responsibility of the individual and DMH to work together to provide meaning, a sense of achievement, and self-direction to the greatest extent possible for the person receiving services. Further, purpose is not static, but grows and changes as the individual progresses.

Persons achieve a sense of purpose by:

- Meeting everyday challenges
- Competency building
- Skill building
- Having meaningful social roles other than their diagnosis or disability (friend, worker, spouse, parent, child, etc.)
- Self-advocacy
- Recognizing and utilizing support and resources
- Meaningful activity
- Community involvement
- Enhancing opportunities for learning about oneself
- Having a way to give back to others

1C. Implications for Services

These concepts have implications for services for consumers, practitioners, and agencies. Later we will make specific recommendations for system change. Here we will describe basic principles.

For *consumers* of DMH services, choice, participation and purpose include:

- Opportunity to grow and change;
- Active involvement in planning supports and services;
- The right to question and be educated on the rationale behind treatment recommendations;
- The right to complete access to their client record and assistance in understanding information in the record;
- Respect for an individual's culture and its particular characteristics.

For *DMH practitioners*, choice, participation and purpose include a commitment by providers to:

- Knowing that individuals are more than their diagnosis;
- Having a genuine holistic relationship with consumers with a focus on overall quality of life rather than on treatment of a diagnosis;
- Affording the consumers maximum opportunities to guide their own growth.

For *DMH agencies*, choice, participation and purpose include:

- A commitment to supporting people receiving services with respect and trust;
- Working together in partnership with individual clients and the particular client communities;
- A mandate to promote these concepts in agency policy and practice.

SECTION 2. EVIDENCE



SECTION 2. EVIDENCE

2A. Overview and Methods

Historically, treatment for populations coping with alcohol and drug addiction, developmental disability, and mental illness has focused on pathology and chronicity—whether to treat the medical symptoms or enforce treatment on patients by professionals who “know better.” Recently, work with persons with each of these challenges has undergone a transformation—from an emphasis on chronic disease and disability (the medical model) to focusing on capacity and capability. Thus, the shift to person-centered treatment in the 1990s has been termed by some as the “decade of recovery” (Anthony, 1991, 2000).

The concepts of choice and self-determination are not new. They are included in the core principles and values of all the major Professional Associations codes of ethics and professional conduct. Examples of this commitment to choice and self-determination include:

- In the National Association of Social Workers’ Code of Ethics, one of their five core values is *Dignity and Worth of the Person*. As a part of the ethical principle based on this value, the code states, “**Social workers promote clients’ socially responsible self-determination. Social workers seek to enhance clients’ capacity and opportunity to change and address their own needs.**”
- In the American Psychological Associations’ Ethical Principles of Psychologists and Code of Conduct, one of their six general principles is *Respect for People’s Rights and Dignity*. As a part of the principle based on this value, the code states, “**They (Psychologists) respect the rights of individuals to privacy, confidentiality, self-determination, and autonomy...**”
- In the American Medical Association’s Fundamental Elements of the Patient-Physician Relationship, it states, “**The patient has the right to make decisions regarding the health care that is recommended by his or her physician.**”
- In the American Dental Association’s Principles of Ethics and Code of Professional Conduct, one of their five principles is *Patient Autonomy* (“self-governance”). The code states, “**The dentist has a duty to respect the patient’s rights to self-determination and confidentiality.**”
- In the American Pharmaceutical Association’s Code of Ethics for Pharmacists, it states, “**A pharmacist promotes the right of self-determination and recognizes individual self-worth by encouraging patients to participate in decisions about their health.**”
- In the Missouri Substance Abuse Counselor Certification Board’s code of ethics it states, “**I shall respect client’s human rights, including their right to make decisions, to participate in any plan made in their interest, even to reject the service being offered.**”
- Self-determination and/or choice are also core elements in the codes of ethics and professional conduct for: the National Therapeutic Recreation Society; the Clinical Social Work Federation; the National Association of Professional Geriatric Care Managers; and others.

Although this vision of consumer participation and independence has generally been accepted across the literature, providers have struggled to turn this concept into workable principles for

delivering services. Further, little evidence documents the extent of this change in vision, or if it has resulted in any consistent change in practices.

One of the major barriers to implementing this vision of choice, participation and purpose has been the variety of terms used to capture this change in service philosophy. A partial list of terms from recent publications include:

- Self determination (Dierwachter, Legget & Bates, 1996; Sands & Wehmeyer),
- Recovery (Anthony, 1991, 2000; Mead & Copeland, 2000; Margolis, Kilpatrick, & Mooney, 2000; Spaniol, Gagne, & Kohler, 1999; White, 2000) and social model of recovery (Dodd, 1997),
- Empowerment (Dickerson, 1998; Klein & Cnaan, 1995; Fischer, 1994),
- Protective factors (Latimer, Newcomb, Winters, & Stinchfield, 2000),
- Resilience (Kirby & Fraser, 1997; Fraser & Galinsky, 1997), and
- Strengths perspective (Saleeby, 1997; Pollio, McDonald, & North, 1996).

Differences in definitions and the focus of terminology across populations and disciplines have further complicated our ability to understand and implement these new principles. Some authors have focused on the experience of the person coping with his/her challenge; other authors have stressed the relationship between the service provider and that person; still other authors emphasize practice principles; while other authors have highlighted agency and system-level changes needed to implement the new principles and practices. Further, identical terms have been used with differing definitions to focus on varying populations. Even within populations and disciplines, acceptance of a term is not always universal. For example, the term “recovery” from mental illness is currently a hotly debated topic, with some arguing for the term as descriptive of a move to maximal independence, while others fear a denial of the long-term nature of the illness.

A second major challenge has been the lack of empirically acceptable evidence supporting this vision. Although there exists a number of moving presentations advocating for this vision using personal narratives and stories, and some qualitative explorations, limited quantitative evidence exists documenting the relationship between this vision and positive consumer outcomes or behaviors.

While little published evidence has supported these concepts, there also has been little evidence documenting the opposite—that choice, participation and purpose are bad for consumers. Thus, in developing these practice guidelines, we have chosen to accept the narrative, qualitative, and limited quantitative evidence, along with expert consensus, to represent the best available evidence supporting the value and definitions within this report.

This section documents the available evidence and how it informs our vision statement. In particular, we will review the evidence related to each of the three service divisions delivered through the DMH: alcohol and drug abuse, mental illness, and developmental disability.

Methods in collecting evidence from the literature

Evidence used in creating this document was identified from a number of sources. Relevant literature was initially provided as part of the charge to the writing team. This included previous work in this area completed by the DMH and other state and national level organizations, which are described in section 4. Since the literature addresses the three populations served by DMH separately using terminology particular to that population and literature, this section will depart from the universal terms of choice, participation and purpose.

An initial search of the scientific literature was conducted using bibliographic searches of relevant databases (MedLine, PSYCinfo, SSCI) for key words of “self determination” and “recovery.” Additional bibliographic information was included from team members with specific expertise, including resilience in youth and family participation. Committee members examined abstracts of the articles identified from this search and articles selected if any individual felt that the article either included empirically derived evidence (including quantitative, qualitative, or rigorous case studies) or included definitions or conceptual discussions potentially useful to the committee task. These full articles were then read by team members and incorporated into the document.

After conducting initial searches and writing first drafts of the evidence sections, it became clear to this committee that the information available was not sufficient to guide us in completing our charge to make specific service recommendations. In discussing how to meet this challenge, we developed a second approach to examining evidence to help us create practice guidelines. For each of the three subsequent sections, we have included a specific focus on the different types of treatments available for persons coping with their particular challenge within the three divisions of DMH. These treatments have been assessed around their incorporation of the principles of choice, participation and purpose. We did not examine effectiveness or efficacy of the individual treatments (except where information was available within the sources or where broad consensus existed)—this task was seen to be far beyond the parameters of the committee. Thus, we will have little or no focus on whether these treatments “work,” but rather on how they relate to our primary focus on choice, participation, and purpose.

In conducting this secondary review, keyword searches were conducted for treatments within the populations. Once a treatment had been identified, the treatment type and relevant terms (e.g., recovery and twelve-step programs) were used to identify potential articles for consideration. The resulting articles were distributed to task groups within the committee, each focusing on specific populations (coping with mental illness, addiction, mental retardation/developmental disability, youth, aging, families). These articles were reviewed by team members and incorporated into relevant sections.

Although the initial charge to the committee recommended using ratings of the articles on empirical methods as a means to assessing the importance of evidence, neither search yielded sufficient numbers of research to consistently inform decisions. To address this limitation, value of the literature was assessed through a consensus by subgroups of committee members. In order to have consensus arise from a varied stakeholder perspective, consensus subgroups included staff, academics, and consumer participants wherever feasible.

2B. Evidence Related to Addiction

Introduction/Recovery in the Addictions field

The concept of recovery has played a central role in determining addictions treatment and is ingrained in the philosophy of the major addiction organizations. The Center for Substance Abuse Treatment (CSAT) of the Substance Abuse and Mental Health Services Administration (SAMHSA) was given a congressional mandate to expand the availability of effective treatment and recovery services for alcohol and drug problems. CSAT is one of the leaders in the annual *Recovery Month* efforts to promote the possibilities for recovery. CSAT has recently developed the *National Treatment Plan Initiative* (CSAT, 2000), which provides an outline for improving substance abuse treatment in America. The *Initiative* identifies a number of issues relevant to the recovery process including the reduction of the stigma associated with treatment, the promotion of client-centered treatment planning, and the matching of clients with appropriate treatment. CSAT has funded the Missouri Recovery Network designed to reduce the denial and stigma surrounding addiction; to educate the public about the recovery process; and to increase opportunities for recovery.

Other organizations are leaders in the recovery effort. The National Association for Alcoholism and Drug Abuse Counselors (NAADAC) is a global organization of addiction professionals "...who enhance the health and recovery of individuals, families, and communities." (NAADAC vision statement). The American Council on Alcoholism (ACA) publishes a quarterly newsletter, *Recovery*, which features articles about recovering from alcoholism. The American Foundation of Addiction Research (AFAR) has identified a long-term goal of understanding the roles of couples and families in the addiction recovery process. The *Recovery Works* Resource Center provides resources on the recovery process for a variety of topics ranging from alcohol and drug addiction to gambling addiction. There are many more organizations, agencies, and other groups dedicated to the concept of recovery.

Definition - Recovery

Recovery, continuing steps toward a positive state of health that includes stabilized symptoms of mental illness, substance abuse or both, meaningful and productive relationships and roles within the community; and a sense of personal well-being, independence, choice and responsibility to the fullest extent possible. (DMH Core rules 9 CSR 10-7.140, 2, SS)

In the addiction field, the term 'recovery' is by far the most frequently used term. Occasionally, terms such as 'self-determination', 'consumer', or 'consumer-directed' are used in the addiction field, but these are not as popular as 'recovery' or 'recoveror.' A new term 'C/S/R' has been used by SAMHSA to denote a Consumer/Survivor/Recoveror who is a person with psychiatric (consumer) and addiction (recoveror) disorders and who has experienced trauma (survivor). A major theme in the discussion of addiction recovery is turning one's life around and finding 'direction.'

Wolf-Branigin and Sawilowsky (1994) surveyed consumers in substance abuse treatment and found that the most important variables related to self determination were self-confidence, positive attitude, listening skills, and responsibility. Connors, Donovan, and DiClemente (2001) speak of a client's self-efficacy, or the ability to effect change.

Addiction Treatment and Choice, Participation and Purpose

The following section examines the relationship between some common addiction treatment theories and choice, participation and purpose. The substance abuse treatment community offers a variety of models, strategies and interventions to address addiction.

Ogborne, Wild, Braun, and Newton-Taylor (1998) surveyed treatment professionals about their beliefs about core processes in substance abuse treatment. Among the highest rated items were those addressing the need to increase clients' acceptance of responsibility; the need to increase clients' confidence in coping without substances; the need to help clients plan and rehearse coping with high-risk situations; the need to help increase clients' sense of self-worth; and, the need to provide clients with an opportunity to provide feedback about treatment interventions.

Forman, Bovasso, and Woody (2001) reported on staff beliefs about substance abuse treatment and noted high agreement for statements calling for increased use of new approaches, research findings, trauma issues, 12-step programs, recovery houses, and treatment matching. Other statements that most respondents agreed on were that co-occurring disorders are common, addiction is a disease, working in the addictions field is rewarding, and that spirituality should be emphasized more. Marinelli-Casey, Domier, and Rawson (2002) have recently addressed strategies for closing the gap between substance abuse researchers and practitioners and called for the introduction and availability of new, evidence-based treatment interventions.

Table 1. Existing approaches and CPP table

This table reviews major categories of service approaches currently used in the field with respect to the extent to which they are consistent with the values of choice, participation and purpose and the extent to which choice, participation and purpose either improve outcomes for that service approach or interfere with obtaining outcomes through that approach. Choice, participation and purpose are extrinsic values that should be adhered to in any instance except those where they can be shown to be directly detrimental and perhaps even then.

- Column 1, Service Approaches – These are service models commonly in use in the field.
- Column 2, Conceptual Support – This rates the extent to which the service approach is supportive of the values of choice, participation and purpose.
- Column 3, Emphasis Improving Outcomes – This rates the extent to which a greater emphasis on choice, participation and purpose has been shown to improve outcomes within this particular service model.
- Column 4, Emphasis Interferes with Outcomes – This rates the extent to which there is evidence that an emphasis on choice, participation and purpose will interfere with this particular service model being effective in producing the desired outcomes.

| <i>Service approaches</i> | <i>Conceptual support for values of choice, participation, and purpose (CPP)</i> | <i>Evidence that CPP emphasis improves outcomes from approach</i> | <i>Evidence that CPP emphasis interferes with outcomes from approach</i> |
|------------------------------------|--|---|--|
| 12 Step Model | Choice High Participation High Purpose High | Choice, participation and purpose are core to this model. | None found |
| Therapeutic Community | Choice Low Participation High Purpose Med | Participation is core to the model. | None found |
| Pharmacotherapy/ Medical | Choice Med Participation Low Purpose Low | Multiple medications are offering more choice. | None found |
| Cognitive therapies | Choice Low Participation High Purpose Low | Participation core to this model. | None found |
| Motivational/ Stages of change | Choice High Participation High Purpose Med | Choice and participation core to this model. | None found |
| Treatment Matching | Choice Med Participation Med Purpose Med | Choice is core to this model. | None found |
| Solution Focused Strength based | Choice High Participation High Purpose High | Participation is core to this model. | None found |
| Harm Reduction | Choice High Participation Med Purpose Low | Choice is core to this model. | None found |

12-Step Model

The 12-step treatment model is based on Alcoholics Anonymous. However the 12-step support group format has been adapted to provide peer supported recovery from a variety of addictions and life problems. Narcotics Anonymous, Cocaine Anonymous, Marijuana Anonymous, Dual Recovery Anonymous, and Overeaters Anonymous are all examples of 12-step peer support and recovery programs. All these programs are based on similar steps and traditions. Steps are the work that the individual does to lead to recovery. These steps might be summarized as follows: admit you have a problem, believe you can get better, turn to others and/or a higher power to help you get better, examine the mistakes you have made in life, correct the wrongs you have done to others during the course of your addiction, and as you get better, help others get better. Traditions are a set of rules to guide 12-step programs in their operations. Twelve-step programs depend on peer support and friendship. The traditions of 12-step support groups are consistent with the values of choice, participation and purpose.

Therapeutic Community

The Therapeutic Community model initially was developed as an intensive long-term residential peer facilitated program for individuals with drug addiction. The highly confrontational program utilizes peer support and feedback to form a new family unit of peers. The program has found

favor in the correctional system both as an addiction treatment model and as a way to manage and modify deviant behavior. The TC programs usually feature highly structured rules and therefore, consumer choice is low. Since the TC program is peer ran participation is high. Development of life purpose is medium as often there is lack of any type of follow-up after release or discharge from the TC; however, the TC program does provide purpose while the consumer is in TC.

Pharmacotherapy/Medical

The medical treatment of addictions includes: Medical management of detoxification, Opioid Maintenance programs, Anatabuse, and Naltrexone. Each of these medical treatments is different. Medical management of detoxification is sometimes necessary for withdrawal. Medical detox sometimes utilizes medication to ease withdrawal symptoms. Opioid maintenance is the substituting of Methadone or other medication for an opiate addiction. Anatabuse is a medication that causes temporary severe distress and illness if mixed with alcohol. Anatabuse has been administered voluntarily and in the past has been mandated in hopes of providing more motivation to abstain from consuming alcohol. Naltrexone is a medication taken to reduce craving for alcohol. Each of these medical treatments should be offered as a client's choice not mandated. The traditional medical model offers low choice, participation and purpose.

Cognitive Therapies

Cognitive therapy focuses on changing thoughts. The belief is that events, thoughts, and behaviors are related and changing one will influence the others. The cognitive therapist takes an active role in the therapy process by helping the client examine the accuracy of their thoughts and beliefs. A related therapy is Rational-Emotive Therapy or RET. Albert Ellis' RET is more challenging and confrontational. Many forms of Relapse prevention therapy are cognitive-behavioral in origin. Choice is moderate to low in this theory; however, the success of cognitive therapy depends on a high level of client participation.

Motivational/Stages of Change

Motivational Interviewing and Enhancement are treatment approaches that are respectful and engaging of the initially involuntary consumer (Higgins and Budney, 1993; Miller and Rollnick, 1991; Miller et al. 1992; Di Clemente and Prochaska, 1998). One of the outcomes of the stages of change efforts has been the development of *Motivational Interviewing* (MI). MI is a strategy to enhance a persons' motivation to change. Unlike confrontational approaches, MI recognizes ambivalence to change and assumes that this is a natural response. Therapists assist the client to work through this ambivalence and move towards changes in behavior. The various techniques used within MI help support the client's sense of self-efficacy and confidence in his ability to change.

Motivational Enhancement Therapy (MET) was designed to combine MI techniques over a briefer time period. Dunn, Deroo, and Rivara (2001) have reviewed interventions adapted from motivational interviewing and found at least one significant behavioral change in the 29 studies they reviewed. However, they conclude that more work is needed to identify the domains, other than addictions, in which it works best and for which types of clients it works best.

Treatment Matching

In *Project MATCH*, a national clinical trial of alcoholism treatment (Project MATCH Research Group, 1997; 1998), patient-treatment matching was tested to assess its relationship to outcomes. *Project MATCH* assessed the effectiveness of motivational enhancement therapy, cognitive behavioral therapy (CBT), and a twelve-step model. Each produced long lasting reduction in alcohol consumption with none of the treatment approaches standing out as more effective (DiClemente, Bellino, & Neavins, 1999). In general, treatment-matching efforts have been designed around the assumption that outcomes can be enhanced when treatment programs address the specific needs and characteristics of clients.

Solution-Focused/Strength-Based Therapies

Solution-Focused Brief Therapy (SFBT) has been offered as an effective approach for the treatment of alcoholism (see for example, Berg, 1995). DeShazer, Berg, and others developed SFBT at the Brief Family Therapy Center. It is a goal-oriented approach that is designed to help clients change target behaviors by helping them develop solutions to the target behaviors. Gingerich and Eisengart (2000) have summarized a number of studies assessing the outcomes of SFBT and include studies involving the treatment of problem drinking (Polk, 1996). In SFBT, the client directs the course of therapy by identifying the goals and outcomes of therapy (deShazer, 1990) and thus earned the characteristic ‘client determined’ (Osborn, 1997). The client’s competencies are identified and used to work towards achievable objectives. Osborn (1997) raised the question of compatibility between SFBT and the disease model of addictions. Results of her research led her to believe that supporting the disease model did not interfere with adoption of SFBT as a treatment intervention.

Harm Reduction Methods

Harm reduction methods are a set of principles and practices that assume a continuum of drug use ranging from nonproblematic to extremely problematic. These methods are aimed at reducing the deleterious effects of substance abuse. These principles and practices assume that a person’s recovery is a long-term endeavor characterized by occasional relapse. Moreover, recovery is a process that involves a number of stages and recognizes that a person may not be able to terminate drug use. The next best thing to abstinence is reducing the harm that drug use causes. Harm reduction is considered a step in the right direction (Denning, 2000). Harm reduction advocates often find themselves at odds with more traditional advocates of the disease model of addiction. Marlatt’s (1998) work is the most comprehensive review of harm reduction. Denning (2000) has extended the original harm reduction thinking by describing the role that psychotherapy can play in reducing the harm of substance abuse. Those practicing harm reduction have employed a number of strategies. Marlatt (1998) identified three types of strategies: policy changes, environmental modifications, and direct work with groups and individuals. Policy changes might include the development of a school policy that protects a substance-abusing student from expulsion, as long as the student receives counseling. An example of an environmental modification is making available a designated driver for persons likely to consume too much alcohol. Strategies directed at individuals and groups assume that those persons are currently using substances but need information about the risks of continued use. An example would be participants discussing risks and consequences of marijuana use and receiving training in dealing with high-risk situations that are likely to lead to use or overuse. The major goal of all of these strategies is to prevent harm.

Related Concepts in the Addictions Field

In general, choice, purpose and participation are valued concepts in the addictions field. However, some treatment interventions are more supportive of these values than others. It is necessary to discuss several related concepts in the addictions field prior to discussing the relationship between treatment methods and recovery.

Mandated Treatment

Almost half (48% FY 2001 ADA statistics) of the consumers in Missouri admitted to Division of Alcohol and Drug Abuse funded addictions treatment are initially mandated or referred by a representative of the legal system. On the surface, this process of intervention and mandated treatment hardly seems like choice. Miller and Flaherty (2000) review the literature on coerced treatment and reach a somewhat different conclusion. They point out that “coerced” treatment is rarely “forced” treatment, rather treatment is often the most attractive choice given “alternative consequences” such as sentencing, loss of job, loss of child, loss of public aid, and others. Coerced treatment in employment situations, for example when an employee is given the choice of losing his job or entering addiction treatment, has been found to be effective in promoting psychosocial functioning (Hoffman & Miller, 1993) and reducing absenteeism, turnover, and medical claims (Normand, Lempert, & O’Brien, 1994). Mandated treatment with the criminal population has also been shown to be effective in reducing criminal activity and increasing psychosocial functioning (Schmidt & Weisner, 1993). Simpson and Friend (1988) demonstrated there was no difference in treatment retention for those referred to treatment by courts versus those referred by other sources such as self, family or friends. Persons arrested for DWI offenses and “coerced” into treatment were significantly less likely to be rearrested for drunk driving than incarcerated offenders (McCarty & Argeriou, 1988). Leukefeld and Tims (1988) edited a classic monograph on compulsory treatment that included a number of examples supporting the efficacy of compulsory treatment. These and other reports suggest that “recovery” is a robust process that is characterized by multifinality. That is, there are a number of roads a person can take to recovery. The degree of choice early in the recovery process (treatment entry) may not be as important as the degree of choices later in the process (maintenance of sobriety). At treatment entry, persons abusing substances are under less self control, have typically encountered family, school, work, health, or law enforcement problems, and have little or no clue about straightening their lives out. Choice later in the recovery process may be more important because the client should be more involved in implementing a recovery plan and maintaining sobriety.

Stages of Change Model

The discussion of denial highlighted the importance of considering the individual’s perception of their addiction as part of the treatment process. As we discussed in the first section, choice is seen as an evolving concept that changes as the individual changes. In understanding addiction and treatment, perhaps the best available construct of change as part of the treatment process is the transtheoretical model (Prochaska & DiClementi, 1982, 1984, 1992; Prochaska, DiClementi, Velicer, et al., 1988). This model has been validated with a variety of populations coping with addictions (Prochaska, Velicer, Rossi, et al., 1994; Prochaska, Norcross, Fowler, et al., 1992; DiClementi, 1993; Snow, Prochaska, Rossi, 1994; Pollio, Spitznagel, North, et al., 2000). The stages of change described for substance abuse include precontemplation, contemplation, preparation, action, and maintenance stages. At the precontemplation stage, motivational

strategies are suggested, and behavioral change should not be the target. At the contemplation and preparation stages, consciousness raising, self-reevaluation, and environmental reevaluation are used. The preparation stage also includes increased commitment or “self-liberation.” At the action and maintenance stages, methods of overt behavior change and behavioral change processes are employed.

Connors, Donovan, and DiClemente (2001) provide a recent look at the role that stages of change play in substance abuse treatment. They recognize that many persons entering substance abuse treatment are resistant or unwilling to change their behaviors. They argue that a logical approach to such resistance is to match treatment interventions to a person’s commitment to change. Moreover, they note that achieving later stage has been related to key clinical outcomes such as reading self-help materials, attending treatment sessions, and other outcomes.

The trans-theoretical model is useful for recognizing the role self-determination plays in recovery. For example, denial and resistance are re-conceptualized as a lack of motivation on the part of the abuser and interventions are designed to increase the abuser’s motivation to change his behavior. Thus, at the pre-contemplation stage, giving the client a number of options provides the client choice. This can be invaluable for overcoming a client’s resistance or resentment resulting from mandated or coerced treatment. In the action and maintenance stages, the client is clearly in charge of his/her plan of action and is receiving feedback about self-efficacy. In this context, relapse presents itself as an opportunity to recycle, to learn from past attempts at change and to reevaluate one’s place in the change process. Clearly, the stages of change model not only supports the values of choice, purpose and participation, but also uses them as foundation concepts.

Consumer Involvement in Treatment

In the addiction field, recent research points to the quality of the therapeutic relationship as a key to engaging the client (Duncan, Hubble, Miller, 1999; Joe, Simpson, Dansereau, & Rowan-Szal, 2001). It is often the presumption of service providers and persons currently coping with addiction that persons in recovery have the best insight into the experience of addiction, and therefore have an advantage in creating the therapeutic alliance. Because of this presumption, the addiction treatment field has a particularly strong history of consumer involvement through organizations such as Alcoholics Anonymous (AA), Narcotics Anonymous (NA), support groups, and Oxford Houses.

The American Society of Addiction Medicine (ASAM) and the American Academy of Addiction Psychiatry (AAAP) developed a public policy statement distinguishing between professional addiction treatment and self-help groups. They recommend that self-help groups should be considered as complementary to professionally directed treatment but not substitutes for professional treatment (<http://www.asam.org/ppol/aaap.htm>).

Role of Choice, Purpose and Participation for the Participant in Service Delivery

Several studies provided direct tests of choice and participation. Calsyn, Winter, and Morse (2000) were unable to demonstrate that consumers having a choice of treatment programs exhibited better substance abuse outcomes in a study of Assertive Community Treatment (ACT) programs. In a study of methadone clients, Kludt, and Perlmutter (1999) were unable to demonstrate differences in outcomes between heroin abusers given a choice in their treatment

planning and those forced to accept treatment as provided. Timko and Moos (1998), in a study of psychiatric and substance abuse programs, demonstrated that policies that gave clients more control and more services were related to programs that were more supportive, expressive, autonomous, and practically oriented. Fiorentine and Anglin (1997) provided evidence from the Los Angeles Target Cities program that increasing participation in outpatient counseling may enhance program effectiveness. Moos and King (1997) showed that participation in treatment was related to more positive outcomes such as completing treatment and moving into a stable residence.

Connecticut Department of Mental Health and Addiction Services

A set of basic premises of recovery has been developed by the People in Recovery to advise the Department of Mental Health and Addiction Services (DMHAS) in the state of Connecticut. These include:

- (1) All individuals are unique and have specific needs, goals, health attitudes and behaviors, and expectations for recovery.
- (2) Persons with mental illness, alcohol or drug addiction, or both, share some similarities, however, management of their own lives and mastery of their own futures may require different pathways at times.
- (3) Regardless of the pathways, all persons shall be offered equal access and opportunity to navigate their road to recovery.
- (4) In order to provide access to the correct road, DMHAS must establish an infrastructure that will allow for easy navigation and progress to the person's destination.
- (5) The infrastructure should not impede the journey; instead, it should ease the travel and create safe transport to the destination.
- (6) DMHAS currently has an infrastructure in place and many of the pathways are in good shape. Some, however, are old and worn, having been designed and built before we had the technology that is currently available. So, some roads have potholes, washed out bridges, unsafe curves, and unnecessary detours.
- (7) There are few different ways to approach the problems. Potholes can be filled in and worn roadways can be given a fresh coat of black top. But these are the short-term, quick fixes that will likely require continued maintenance.
- (8) Long-term and effective solutions will require re-engineering and a significant commitment to re-building.

The Connecticut group also addresses core values for *participation*.

- (1) There shall be no wrong doors when entering into the DMHAS mental health and addictions treatment system.
- (2) Nobody who requests services can be refused without first being offered a full intake interview and be provided with a written explanation if refused.
- (3) An individual may enter any appropriate level of care when needed not just at times of crisis.
- (4) An individual's choice must be respected in all matters related to his/her treatment.
- (5) Every person has the right to participate, or not participate in treatment, as he/she sees fit. People may, from time to time, be able to step away from services without receiving threats, given artificial consequences, or experience barriers to re-engagement.

- (6) Providers shall value the treatment goals identified by the person in recovery and will include those goals as the basis for evaluating outcomes

2C. Evidence Related to Recovery from Mental Illness

Introduction/Definition

Concepts of choice, participation and purpose remain controversial for services for persons with mental illness, both for consumers and providers. Although recovery is a term that appears to be increasingly accepted for persons coping with mental illness—in part because of advances in treatment—we will not use it here as our core term. Rather, we will focus on the components as defined in this document.

The Department of Mental Health and this paper use this definition of recovery: Continuing steps toward a positive state of health that includes stabilized symptoms of mental illness, substance abuse or both, meaningful and productive relationships and roles within the community; and a sense of personal well-being, independence, choice and responsibility to the fullest extent possible. (DMH Core rules 9 CSR 10-7.140, 2, SS)

Participant Roles

Limited evidence suggests that traditional services, philosophies, and models may actually promote a self-perception of helplessness among mental health consumers; the so-called “patient role.” Personal experiences related by consumers indicate that many have become comfortable in this role and, therefore, have based their self-identification around their mental illness (Mead & Copeland, 2000). Conceptual models indicate that an illness-oriented treatment model encourages people with severe mental illness to accept lives of chronic disability and passivity (Mead & Copeland, 2000; Dickerson, 1998).

Davidson and Strauss speculate that while clinicians do not deliberately instill helplessness, the consumers’ capacity for responsible self-determination in regard to medication and other health management issues is sufficiently unsettling as to require reconsideration by many clinicians of their traditional roles (Davidson & Strauss, 1992). Personal experiences related by consumers and conversations with providers indicate that mental health care professionals occasionally equate self-determination with “non-compliant” and fear that their “patient” will become dangerous either to self or to others if allowed to participate in treatment decisions (Mead & Copeland, 2000).

However, there is reason to believe, based on consumer interviews and limited qualitative research, that with effective community-based supports in place, self-determination and recovery are no less realistic for an individual with a mental illness than for any other member of the population. Personal accounts, as well as qualitative research on the subjects of self-determination and recovery from mental illness, indicate that with effective supports in place, the consumer gains a stronger sense of self that is separate from his or her illness and this strength subsequently allows the individual to develop increasing confidence in his or her own self-care and decision making skills (Davidson & Strauss, 1992; Young & Ensing, 1999). Literature also indicates that as self-confidence and decision-making skills grow, the individual develops additional coping skills and a new level of self-awareness, which assist with symptom recognition and control (Mead & Copeland, 2000; Davidson & Strauss, 1992; Young & Ensing,

1999). As the capacity to make informed choices regarding mental health care increases, the level of external controls and supports required by the individual decrease. Also, symptoms which interfere with life will appear less frequently (Young & Ensing 1999; Mead & Copeland, 2000; Anthony, 2000; Anthony, 1993; Yanos, Primavera & Knight, 2001), allowing the individual to enjoy life centered on his or her desired and varied goals as opposed to having one's mental illness dominate each and every aspect of the person's life.

Processes of Recovery

Qualitative studies, in which individuals and focus group participants were interviewed regarding the processes of recovery, indicate that different supports are needed at different stages of the growth process. The initial stage or awareness of a serious mental illness, when symptoms are usually acute, can leave one with no internal locus of control (Davidson & Straus, 1992; Young & Ensing, 1999). According to individual accounts, this period, during which diagnosis is usually made and medications started can create a sense of dependency during which basic self-care becomes a challenge (Young & Ensing, 1999). The supports and services provided during this stage, such as counseling to accept one's diagnosis and assistance with basic care, would differ greatly from those that are needed once the individual has determined it is time to return to work or school. At this stage the individual will benefit more from organizational assistance, self-advocacy education, and community resource referrals, such as vocational and educational rehabilitation. Anthony cites work by the National Institute of Mental Health and The Center for Mental Health Services which initiated a number of research demonstrations of essential Consumer Support System service components, including vocational rehabilitation, case management, crisis response services, and other supportive services. Analysis of 29 projects found that the majority of the studies reported positive findings on one or more of the following outcomes: reduced symptomatology, better consumer outcomes, increased satisfaction with services, and more efficient service utilization. Therefore, it is in the best interests of all stakeholders to identify as many support options as possible (Davidson & Strauss, 1992; Anthony, 2000; Anthony, 1993).

Anthony defines the Community Support Services (CSS) concept, first envisioned by the National Institute of Mental Health in the mid-1970's, as one that "identifies the essential components needed by a community to provide adequate services and support to persons who are psychiatrically disabled" (Anthony, 1993). Realistically, the types of supports that are available to an individual with a mental illness are dependent largely on the resources of both the family and the community in which he or she lives (Young & Ensing, 1999; Dickerson, 1998).

Self-Determination and Treatment Models

Certain models of mental health services, both provided within mental health services systems as well as allied to them, include self-determination and recovery as core concepts. These models include peer support groups, clubhouses, and case management. Personal accounts and qualitative evidence from consumers provide evidence for the inclusion of these concepts.

Table 2: Existing approaches and CPP table

This table reviews major categories of service approaches currently used in the field with respect to the extent to which they are consistent with the values of choice, participation and purpose and the extent to which choice, participation and purpose either improve outcomes for that service

approach or interfere with obtaining outcomes through that approach. Choice, participation and purpose are extrinsic values that should be adhered to in any instance except those where they can be shown to be directly detrimental and perhaps even then.

- Column 1, Service Approaches – These are service models commonly in use in the field.
- Column 2, Conceptual Support – This rates the extent to which the service approach is supportive of the values of choice, participation and purpose.
- Column 3, Emphasis Improving Outcomes – This rates the extent to which a greater emphasis on choice, participation and purpose has been shown to improve outcomes within this particular service model.
- Column 4, Emphasis Interferes with Outcomes – This rates the extent to which there is evidence that an emphasis on choice, participation and purpose will interfere with this particular service model being effective in producing the desired outcomes.

| <i>Service approaches</i> | <i>Conceptual support for values of choice, participation, and purpose (CPP)</i> | <i>Evidence that CPP emphasis improves outcomes from approach</i> | <i>Evidence that CPP emphasis interferes with outcomes from approach</i> |
|--|---|--|---|
| Psychosocial Rehabilitation Clubhouses | Peer treatment, independence focus | Not studied | Not studied |
| PACT/CTT | Generally low | Recent inclusion of peer/consumer as team member | None found |
| Case management | Varies, but generally low | Limited quantitative evidence, but ample qualitative/professional literature | None found |
| Peer support groups | Peer support (NAMI, NDMDA) | Increased coping strategies, empowerment | None found |
| Supported employment | Varies, but generally high; independence focus; problem solving; confidence building | Increased self-awareness, self-trust, socialization | None found |
| Service animals | SA varies but generally high for individual application; independence focused | Increased sense of independence, responsibility, self care | None found |
| Skill training | Builds skills that facilitate participation | Improved outcome when skill is relevant to client | None found |
| Patient education | Patient education | Participant focus on education/problem solving enhanced symptom self-management, trust in self and providers | None Found |

| | | | |
|--------------------|---------------------------------------|---|------------|
| Multifamily groups | Family focus; support and education | Current studies of family-responsive models | None found |
| Warm lines | Emphasizes autonomy and “giving back” | Cannot be done without CPP | None found |
| Advance directive | Focus on competence of participant | Increased empowerment, sense of competence | None found |

PACT/CTT

Programs in Assertive Community Treatment (PACT) represent the gold standard in evidence-based practice (Dixon, 2000). Characterized by its founder as “hospitals without walls” PACT is characterized by an extremely paternalistic approach to treatment. Features of the model include extremely small caseloads for team members, providing much of the services within the team itself, and ongoing (and often intrusive) support for everything from medication management to household maintenance (Lehman & Steinwachs, 1998; Scott & Dixon, 1995).

Recently, adaptations of PACT have been created which include consumer members. Recent research (including a random assignment trial) has suggested that these adaptations are as effective as traditional PACT, as well as achieving greater numbers of visits and more consumer-friendly culture (Calsyn, Winter & Morse, 2000; Paulson, Herinckx, Demmler et al., 1999). Although the shape and form through which consumers can participate in PACT varies from radical revisions such as PACE (Personal Assistance in Community Living: Fisher & Ahern, 2000) to inclusion of members as unskilled case managers.

Peer Support Groups

Peer support groups vary from small gatherings sponsored by local community treatment centers to those established through national organizations. They may be diagnosis-specific as is the National Depressive Manic-Depressive Association (NDMDA; Dickerson, 1998), or have a broader scope welcoming any person with any diagnosis of mental illness, as demonstrated by the National Alliance for the Mentally Ill (NAMI). Both of these national organizations sponsor local chapters that offer support, education, advocacy, and self-advocacy education. In addition, NAMI provides education, support groups, and services for family members as well. Frequently, peer support and advocacy groups are operated solely by primary consumers and/or families of consumers, as is the case with NAMI (Dickerson, 1998; NAMI). Common themes for these peer support groups are wellness and empowerment. Individuals are given the opportunity to connect with, and become, role models and share coping strategies and information in an accepting, stigma-free environment (Yanos, et al, 2001; Mead and Copeland, 2000; Young & Ensing, 1999; Dickerson, 1998). Evidence for the positive impact of these organizations is limited; however, it supports the impact of peer interactions on service participation (Powell et al., 1995), which we have previously argued as a key component in achieving change.

Psychosocial Rehabilitation Clubhouse

The clubhouse model shares the emphases of empowerment, wellness, and acceptance with peer groups, but expands upon it through an emphasis on employment and independence. The clubhouse approach is a group-oriented program in which participants are responsible for conducting the tasks related to the daily functioning of the program. Clubhouse staff and participants work together to make decisions regarding programs and activities and participants

are encouraged to prepare for work or school outside of the clubhouse environment. Job placement is frequently made available with transitional employment supports provided (Dickerson, 1998). Again, evidence in support of this model is limited, but that which exists supports the model's utility.

Case Management

On the surface, case management appears to be the antithesis of self-determination. It can, however, be the impetus to individual learning. The key precepts and words with case management are assessment, planning, goals, and interventions. Ideally, the case manager and consumer work together to assess the needs and goals of the individual and jointly construct plans to meet those needs and goals. The case manager assists the individual in learning to advocate and intervene on his or her own behalf (Anthony, 2000). Case management that incorporates self-determination is different from traditional models and will be specified in our final section. Several constructs of case management are based on the presumption of client self-empowerment and capacity building (e.g., strengths perspective, Saleebey, 1997).

Supported Employment

Supported Employment Programs provide individual placements and competitive employment at community jobs paying at least minimum wage that any person can apply for in accord with client choices and capabilities. The supportive employment approach does not screen people for work readiness or require extended pre-vocational training. It helps all who say they want to work without use of prevocational work units, transitional employment or sheltered workshops. Key services include identifying employers and improving their knowledge and comfort levels with respect to mental illness. The provider accompanies clients on interviews and providing ongoing support once the client is employed. Supportive employment has been found effective in increasing rates of employment in 8 randomized controlled trials and 3 quasi-experimental trials (Bond & Becker, March 2001). The studies include settings with significant levels of Caucasians, African Americans and Latino populations showing that the approach is effective across diverse cultural groups (Drake and McHugo, 1999). Five randomized and three non-randomized studies comparing supportive employment treatment with day treatment or transitional employment programs have shown overall service costs tend to be lower but the differences are not significant (Clark & Bush, 1996). Consumer earnings increase only slightly on average compared to other programs (Latimer, August 2001). Outcomes were also improved in programs that provided services in the community and used fulltime employment specialists as opposed to staff with mixed roles (Becker & Smith, 2001) and when teams integrate mental health and vocational services on the same team (Bond & Drake, March 1997). The supported employment model has been proven effective as a statewide approach with both Ohio and New Hampshire achieving significant increases in competitive employment among persons served by their state mental health authority (Bond & Becker, March 2001).

Supportive employment, particularly the most common model-Individual Placement and Support is highly consistent with the values of recovery and self-determination in that it emphasizes individualized job placement according to client preferences and participation in the regular community job market.

Success in supportive employment has been shown to be unrelated to individual client clinical characteristics such as diagnosis or duration of illness but was directly related to provider advocacy on issues not related to employment, suggesting that an emphasis on recovery and self-determination values is likely to improve the effectiveness of supported employment (Jones & Perkins, 2001 and Banks and Charleston, 2001).

Service Animals

A psychiatric service dog is separate from a therapy animal in that, like other service animals, it is specific to its owner's needs and performs basic functions that the owner is unable to provide for him or herself (ADA, 1990). Limited controlled studies on the value of animal assisted therapy in the psychiatric setting have shown evidence of significantly decreased anxiety, depression, aggression, and anger (Barker and Dawson, 1998; Barak 2001), as well as increased socialization skills and attention spans (Barak, 2001; Barker and Dawson, 1998), self care skills (Barak, 2001) and communication skills (Barker, 1999). Given the information thus far received, animal assisted therapy in general and service animal use specifically, while still considered unconventional, appears to be a highly effective intervention for some consumers.

The use of a service dog to assist with a psychiatric illness is determined by the consumer's desire to make use of this resource. When used, the dog is individually trained to advance the owner's independence. Dogs may be trained for such specific tasks as:

- Bringing medication or reminding of medication times
- Bringing an emergency phone, or using a K-9 rescue phone preset to 911 to summon help
- Providing balance support while walking or on stairs
- Leading the human partner to a safe place during a panic, disassociative or other episode
- Awakening human partner for school or work

Dogs are also used in less quantifiable but equally valid tasks including (Deegan, 1999; Froling, 1998):

- Providing a reality check during a hallucination or flashbacks
- Tactile stimulation during disassociative/depersonalization episodes
- Provide a "safe person" for those who have severe social phobia or agoraphobia
- Alert the owner to symptomatic behaviors
- Provide focal point on which to concentrate

Advance Directives

The use of advance directives and durable powers of attorney for health care decisions is not only encouraged, but federal mandate, in the form of the Patient Self-Determination Act of 1994, directs that any health care facility participating in Medicare/Medicaid programs make information regarding this option available and assist with implementation if the patient and family choose (Fleischer, 2002). Furthermore, health care providers are obligated by law to honor the conditions of the directives. Advance directives for mental health care needs serve the same purpose as do those for other health care. They specify the consumer's treatment preferences in the event that he or she is unable to do so and may designate an agent to make decisions on behalf of the consumer.

In the event of involuntary hospitalization, an advance directive executed by a designated agent can reduce or eliminate unnecessary treatments by specifying what has or has not been effective in the past (NMHA); prevent forced treatment (Bazelon, 2001); enhance individual autonomy, recovery and empowerment (NMHA); improve physician/consumer communication (Bazelon, 2001; NMHA); reduce the risk of crises resulting in safety measures such as physical or chemical restraint or involuntary retention (NMHA).

Patient Education

Consumer education generally includes one of three areas: diagnosis related information, resource options, and self-determination/advocacy skills (Young & Ensing, 1999; Fisher, 2002). Education of the consumer in these areas has been related to decreased dependency, heightened self-awareness, increased symptom self-management, and decreased symptom interference (Anthony 1993; Spaniol, Gagne, & Koehler, 1999; Young & Ensing, 1999; Fisher, 2002). Education should be pervasive, in that one or more facets are included in all areas of support, continuous, and graduated in order to provide the appropriate level of information as determined by the level of consumer functioning (Anthony, 1993). A consumer who is knowledgeable regarding his or her diagnosis and resources, and having learned to self advocate has been shown to become a more active participant in his or her care resulting in a separation of the diagnosis from the self (Davidson & Strauss, 1992; Spaniol, Gagne, & Koehler, 1999; Mead & Copeland, 2000). The education process is based on the premise that the consumer is, or soon will be, capable of making his or her own decisions and therefore has the right to receive all of the information necessary to make an informed choice.

Skill Training

Psychosocial Skills Training is a highly interactive, structured, systematic, educational approach to therapy. Skills trainers use active teaching methods such as didactic instruction, modeling, behavior rehearsal, proaching of desired responses, corrective feedback, contingent social reinforcement, and homework assignments to facilitate the acquisition of new competencies. Persons are taught to sequentially, gradually combine simpler behaviors into more complex patterns in both individual and group formats. Psychosocial skills training has not been used uniformly with all persons with mental illness. The sole focus in the adult population is for persons with Schizophrenia. It has also been used in children with autism and conduct disorder.

Psychosocial Skills Training for adults with Schizophrenia has been extensively researched. It is recommended as effective in the Schizophrenia Patient Outcomes Research Team practice guideline (PORT, Scott and Dixon, 1995) and in the American Psychiatric Association Practice Guideline for Schizophrenia (Lehman et al. 1998). Four subsequent literature reviews (Scott and Dixon 1995, Penn & Mueser 1996, Dilk & Bond 1996 and Heinssen & Liberman 2001) have consistently concluded that it is effective in helping persons with Schizophrenia obtain a wide range of social and instrumental competencies. Skills training has a moderate impact on psychiatric symptoms, relapse, and hospitalization. The evidence that persons with schizophrenia apply the skills learned in training programs to real life situations is much scantier, and there is little evidence on long-term outcomes.

The basic values of Psycho-Social Skills Training is not particularly consistent with the values of choice, participation and purpose; however, psychosocial skills training has consistently been

shown to have a positive effect on the person's perceptions of themselves as more assertive and less socially anxious after treatment.

There is moderate evidence that Psycho-Social Skills Training outcomes are enhanced by a Recovery approach consistent with choice, participation and purpose. Several researchers and experts in the field stress the importance of assessing the person's expectations regarding targets, goals, and outcomes (Corrigan et. al 1990, Heinssen et. al 1995, Fenton et al 1997) urging that the skills training method should take into account the person's view of their problem and their own personal goals and that the treatment plan should reflect the person's aspirations for growth. Three studies (Miller and Rollnick 1991, Ziedonis and George 1998, Addington et. al. 1998) have reported improved outcomes in a psycho-social skills training that utilize motivation and enhancement therapy and a readiness for change model approach (Prochaska & DiClement 1983).

Warm Lines

Warm lines are telephone peer counseling operated for and by persons with mental illness. They provide supportive and pre-crisis counseling but are not intended to assist persons whose situations present an imminent risk of danger. Research on the effectiveness and outcomes of warm lines is extremely limited. There are three program description reports, no review articles and no controlled randomized trials. (Lane March 1998) reported on a warm line program that was developed as a cost effective method of providing support services during weekends and holidays when the community mental health center was closed. Peer Counselors were reported to achieve rehabilitation goals such as increased socialization and improved interpersonal skills faster than clients that did not provide peer counseling. Peer Counselors were more likely to achieve competitive employment and independent housing. Publinski (2001) reviewed three peer run warm lines and reported benefits to both counselors and callers in terms of increased social connectedness, increased autonomy from professional care delivery systems, and improved problem solving. Warm lines are strongly consistent with the values of recovery and self-determination in their emphasis on participation, as a way of giving back and helping others, and with their emphasis on a relationship between equals.

Multifamily Groups

Family participation in services (particularly through multifamily groups) has been associated with a wide variety of gains for both the family and the person with illness in a number of random assignment trials. Significant gains for the family member with severe mental illness include: less relapse (Leff, et al. 1982, 1985, 1988, 1990; Falloon, et al., 1982, 1985, 1987; Anderson, et al., 1986; Hogarty, et al., 1986; Tarrier, et al., 1988, 1989; Levene, et al., 1989; McFarlane, et al., 1993, 1995; North et al., 1998), reduced psychiatric symptoms (McFarlane, et al., 1993; Falloon, et al., 1982, 1985, 1987), and improved social functioning (Leff, 1988, 1990; Levene, et al., 1989; McFarlane, et al., 1993). Gains for supporting family members include improved social and family adjustment (Falloon, et al., 1982, 1985, 1987; Doane, et al., 1986; Solomon, et al., 1996a, 1996b, 1997) and relief of family burden (Lam, 1991; Dixon & Lehman, 1995). Based on this research, the evidence strongly supports inclusion of the family as collaborators in person-centered growth, and argues for outreach to active family members and social supports.

2D. Evidence Related to Self Determination in Developmental Disability

The principle of self-determination is a core value in our culture and has been at the heart of every emancipation and civil rights movement throughout the world. Powers, Singer, and Sowers (1996) conceptualised self-determination as a crucial component of the development of a competent person. Wehmeyer, Agrin, and Hughes (1998) concluded that “people who are self-determined act autonomously, self-regulate their behavior, and are psychologically empowered and self-realizing” (p.7). Without meaningful opportunities to make choices, people are bereft of an important, appropriate means for creating a rich personal lifestyle (Baker, Horner, Sappington, & Ard, 2000). Choice has been identified as an essential component to quality of life (Hughes, Hwang, Kim, Eisenman, & Killian, 1995; O’Brien, 1987).

Support for self-determination and empowerment has grown rapidly in the field of the professional and research literature (e.g., Brotherson, Cook, Cunconan-Lahr, & Wehmeyer, 1995; Johnson, 1999; Olney & Salomone, 1992; Powers, Singer, & Sowers, 1996; Sands & Kozleski, 1994; Schloss, Alper, & Jayne, 1994; Wehmer, 1992a, 1994, 2000). Ward and Halloran (1993) argued that self-determination is the ultimate goal of education.

Rights to freedom, equality, equal protection under the law, and control over their own lives have often been disregarded for people with disabilities. Research also suggests that adults with disabilities make fewer choices than do peers without disability (Kishi, Teelucksingh, Zoolers, Park-Lee, & Meyer, 1988; Parsons, McCan, & Reid, 1993; Tossebro, 1995) and have restricted opportunities for control and choice (Johnson, 1999; Wehmeyer, Kelchner, & Richards, 1995; Wehmeyer & Metzler, 1995). There is also substantial evidence of barriers to people with disabilities attaining self-determination including: attitudes of others toward people with disabilities, socio-economic factors, the person’s self-concept and confidence, a person’s living environment, a person’s competencies and capacities, paternalistic service delivery systems, overprotection, and prejudice (Baker, Horner, Sappington, & Ard, 2000; Brown, Belz, Corsi, & Wenig, 1993; Campbell, 1991; Dudley, 2000; First International Conference on Self-Determination and Individualized Funding, Seattle, July 2000; Guess & Siegel-Causy, 1985; Higgins, 1992; Johnson, 1999; Kennedy, 2001; Kosciulek, 1999; Moseley, 1999; Olney, 2001; Parent, 1993; Scotch & Schriener, 1997; Shevin & Klien, 1984; Stalker & Harris 1998; Stancliffe, 1997; Stancliffe et al, 2000; Stancliffe & Abery, 1997; Stancliffe, & Paramenter, 1999; Stancliffe & Wehmeyer, 1995; Szymanski & Trueba, 1994; Tossebro, 1995; Wehmeyer, 1992b, 1998, 1999, 2000; Wehmeyer, Agran, & Hughes 1998; Wehmeyer & Metzler, 1995; West, Kregel & Revell, 1994; West & Parent, 1992; Williams, 1991).

There are many examples of how people with developmental disabilities are not supported to become self-determined. The present service delivery system in most states is based on prearranged services and allocating people with disabilities to predetermined categories (Smith, 1994). This rationale is based on the assumption that people with disabilities and their families are passive subjects, whose care and treatment must be prescribed and managed by professionals (Smith, 1994). Consider the once widely accepted practice of all adult people with a label of mental retardation automatically receiving a guardian to make all their decisions for them, even though they were capable of making decisions for themselves (Stancliffe et al, 2000), thus denying them the opportunities to make choices, act autonomously, self-regulate behavior, and become self-realizing competent individuals.

Definition - Self-Determination:

According to the American Heritage Dictionary of the English Language, Third Edition, *Self-determination* is defined as “Determination of one’s own fate or course of action without compulsion.” Many different definitions of self-determination have emerged in research literature and although there are similarities among these definitions, there are also distinct differences.

When applied to developmental disabilities, self-determination often gets too narrowly interpreted as reflecting either choice making or self-advocacy. The literature presents two major conceptual approaches that provide a definitional framework within which intervention and policy development regarding self-determination can occur. These two conceptual approaches frame self-determination as a motivational construct and as an empowerment issue (Wehmeyer, 1996). For this document, self-determination is defined as the ability internally, within the person, and externally, in the environment, to choose and use the services and supports necessary to exercise the same rights as other citizens.

Self-Determination as a Motivational Construct:

Deci and Ryan (1985) refer to self-determination as an internal need contributing to an individual’s performance of intrinsically motivated behaviors, “the innate, natural propensity to engage in one’s interests and exercise one’s capacities, and in so doing, to seek and conquer optimal challenges” (p.43). Self-determined activity involves a full sense of wanting, choosing, and personal endorsement (Deci et al. 1992).

Self-determination is the attitudes, abilities, and skills that lead people to define goals for themselves and to take the initiative to reach these goals. The traits underlying self-determination include self-actualization, assertiveness, creativity, pride, and self-advocacy (Ward, 1988). Self-determination is one’s ability to define and achieve goals based on a foundation of knowing and valuing oneself (Fields & Hoffman, 1994).

“It (self determination) is a declaration of one’s individuality: the desire to change and control one’s surroundings to better meet one’s needs.” (Olney, 1999, p.3)

Self-Determination as an Empowerment Issue:

The term *self-determination* is used by disability rights advocates and people with disabilities to refer to their “right” to have control in their lives (e.g. Nirje, 1972). In this context, self-determination and empowerment are often used interchangeably and as Rappaport (1981) states, usually in reference to actions that “enhance the possibilities for people to control their lives” (p.15).

Nirje (1972) equates self-determination with the respect and dignity to which all people are entitled. Self-determination is fundamental to attaining respect and dignity and to perceiving oneself as worthy and valued. It is a major reason people with disabilities have been unequivocal and consistent in their demand for control in their lives (Wehmeyer, 1996).

Self-determination represents a broad concept related to individuals' overall control of their lives and ability to participate fully in society and rests on four basic principles: 1) freedom to exercise the same rights as other citizens, 2) authority to control the funding needed for services and support, 3) support through the organization of resources as determined by the person with the disability, and 4) responsibility to use public dollars wisely (Nerney, Crowley, & Koappel, 1995; Nerney & Shumway, 1996; Scala & Nerney 2000).

Self-determination is the concept of affording people with disabilities and their families and caregivers direct control over financial resources, allowing them to personally choose services and supports they desire, thus allowing them direct authority over their own lives (Bowman, 1999; Ficker-Terrill, 1998; Yuskauskas, Conroy, & Elks, 1997).

The underlying assumption of self-determination is that all adults can and should have control over their own lives, given appropriate supports (Bambera, Cole, & Koger, 1998; Olney, 2001). Hughes and Agran (1998) delineated four facets of self-determination:

1. Skills used to manipulate the environment, shaped by individual's experiences,
2. Internal drive and ability to choose and act in accordance with one's needs,
3. Shared communication within social relationships, and
4. Political action.

Empowering processes are those in which people create or are given opportunities to control their own destiny and influence the decisions that affect their lives (Boston & Brookings, 1996; Hahn, 1991; Zimmerman, 1995). These processes provide individuals the opportunity to achieve goals, obtain greater access to and control over resources, and gain mastery over their lives (Cornell Empowerment Group, 1989; Mechanic, 1991; Zimmerman, 1990).

Self-determination does not require or equate with independent performance, self-reliance, self-sufficiency, or having the capacity to perform every behavior oneself. Self-determination is not just choice nor is it absolute control. Self-determination is about being the causal agent in one's own life (Wehmeyer, 1996). Self-determination refers to acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference (Wehmeyer, 1992a, 1995).

Self-determination represents a set of attitudes (psychological empowerment and self-realization) and abilities (behavioral autonomy and self-regulation). Essential characteristics of self-determination include: 1) an individual acting autonomously, 2) behaviors being self-regulated, 3) the person initiating and responding to event(s) in a "psychologically empowered" manner, and 4) the person acting in a self-realizing manner (Wehmeyer, 1996).

People who act in a psychologically empowered manner do so on the basis of a belief that: 1) they have control over circumstances that are important to them (internal locus of control); 2) they possess the skills to achieve desired results (self-efficacy); and 3) if they choose to apply those skills, the identified results will come about (outcome expectation) (Wehmeyer, 1996).

Role of Choice, Participation, & Purpose (CPP) for the participant in service delivery:

Consumer direction as a philosophy emphasizes consumers' capacity to "assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (National Institute of Consumer-Directed Long-Term Services, 1996). As a practice, consumer-direction consists of consumers making decisions and managing delivery of long-term-care services (Kosciulek, 1999; Scala & Nerney 2000).

Consumer-directed disability policy and rehabilitation programming should be based on the presumption that consumers with disabilities are the experts on their service needs. An informed consumer is the best authority on what his or her service needs are, how these needs are best met, and whether these needs are being met appropriately. The consumer should be presumed competent to direct services and make choices, regardless of age, or the nature or extent of disability". (National Institute of Consumer-Directed Long-Term Services, 1996).

The self-determination movement has developed through the active collaboration of individuals with disabilities, their family members and other allies, and professionals. Key legislation, most notably, the Rehabilitation Act of 1973 (and subsequent amendments), Individuals with Disabilities Education Act (IDEA) (P.L. 99457, 1986 and subsequent amendments), and the American with Disabilities Act (ADA) of 1990 (P.L.101-336), are the direct result of advocacy of, by, and for people with disabilities.

Several key self-determination initiatives have been implemented, such as Partners in Policy-making; the Administration of Developmental Disabilities' Projects of National Significance focused on home ownership and personal assistance services; model self-determination projects funded by the Office of Special Education, which from 1990 to 1996 funded 26 model demonstration and five assessment development projects to promote self-determination for youth with disabilities (Ward & Kohler, 1996); family and individual empowerment projects supported by the National Institute on Disability and Rehabilitation Research and Rehabilitation Services Administration; and a series on consumer-directed system development projects funded through the Robert Wood Johnson Foundation (Nerney & Shumway, 1996; O'Brien, 1997) and the U.S. Department of Health and Human Services. These projects and other education-related efforts resulted in numerous frameworks with which the term self-determination was defined and activities developed (Abery, 1993; Agran, 1997; Field & Hoffman, 1994; Johnson, 1999; Martin & Marshall, 1996; Mithaug, 1996; Powers et al., 1996; Sands & Wehmeyer, 1996; Wehmeyer, Agran & Hughes, 1998).

For years professionals have been urging the development of supports and services that will help people with developmental disabilities become "self-determined" (Wehmeyer & Metzler, 1995). Current philosophical goals of the service delivery system include societal inclusion, self-determination, person-centered planning, and greater self-sufficiency, yet these goals are still far from being met for most people with disabilities (Dudley, 2000; Hayden & Abery, 1994; O'Brien, O'Brien, & Mount, 1997; Sands & Wehmeyer, 1996; Wehmeyer & Metzler, 1995).

Many agencies are involving people with disabilities in their own planning conferences, but do not allow them to assume a significant role in evaluating their own service plans or in making decisions about their residential or work arrangements (O'Brien et al., 1997). People with

disabilities' needs are often overlooked or ignored because other people participating assume that they are incapable of verbalizing their "true" desires and needs (Dudley, 2000).

In both employment and community living, consumers with disabilities have not been given a range of service options. Traditionally, the range has been from a single option to a few constricted options (Kosciulek, 1999; Taylor, Biklen, & Knoll, 1989; West & Parent, 1992).

Wehmeyer and Metzler's (1995) study assessing the degree to which people with mental retardation are self-determined found several trends responsible for the lack of self-determination among people with developmental disabilities including:

- 1) The perception by professionals, families and support staff that people with developmental disabilities do not possess the abilities or cognitive capacity to make choices other than deciding what they will wear or what they will do with their leisure time. Making decisions about medical treatment or whether or not to marry and whom are a few of the choices that historically have been taken out of the hands of people with developmental disabilities.
- 2) There are also socioeconomic factors that limit the ability of people with developmental disabilities to exercise self-determination. For example, it is difficult to decide to live in your own home when one is living in poverty.
- 3) In order for self-determination to be a reality for people with developmental disabilities, they need to believe that they have real opportunities for making choices and having control in their lives.

Additional support for building capacity and skills as a route to realistic self-determination also is found in Sowers and Powers (1995), who suggest that after students with multiple disabilities have the opportunity to learn and use a skill (like ordering a meal at a local fast food restaurant) their self-confidence increased.

Self-Determination is, in fact, a concept that has taken on a life of its own in the support of people with developmental disabilities. There have been recent efforts to develop "self-determination" projects around the country through the Robert Wood Johnson (RWJ) self-determination grants that were awarded to 19 states. (Moseley, 1999) These projects are designed to support people with disabilities and their families to direct their own services and design their own supports with the help of "brokers or support coordinators." Primary consumers and families are in the lead, not the professionals.

Wehmeyer and Schwartz (1998) examined the link between self-determination and quality of life for adults with mental retardation. This research showed that self-determination status predicted membership in the higher quality of life group, validating the model's alignment of self-determination with numerous positive outcomes, providing support for increased attention to promoting self-determination for youth with disabilities.

If individuals with severe disabilities are to be empowered, professionals, caregivers, friends, and family members must become competent communication partners, learning to understand and respect the person's autonomy and competence. As Brown, Golthef, Guess, and Lehr (1998) noted, rather than commanding and enforcing obedience, the goal of interactions should be

expanding understanding of desires and increasing opportunities for real choice. “Often the person with a disability is asked to change his or her behaviors to satisfy the needs and desires of those without disabilities. A critical component in supporting an individual’s right to self determination is willingness of the communication partner to also change” (Olney, 2001 p. 7).

Moseley (1999), co-director of the National Program Office, Self-Determination for People with Developmental Disabilities, cites several themes taken from a questionnaire given to participants in the 19 states that relate to the success of implementing self-determination programs. The most prevalent themes include:

- 1) System change is necessary: the way states currently do business does not support the basic concepts of self-determination;
- 2) This effort must involve all stakeholders working together as equal partners; and
- 3) An understanding that “self-determination” involves professionals, support staff and people with disabilities gaining new skills through enhanced training is important to the success of the effort.

There are stories shared by people with disabilities about their journey to becoming “self-determined.” Michael Kennedy, a self-advocate for example, has spoken about how his perception of self-determination has changed as he has experienced new opportunities:

“When I was in the institutions, I had to make sure I got the basic care I needed, like my personal hygiene and three meals a day, that was what self-determination meant at that time. There, the caregivers seemed to think people didn’t know what they wanted or how they wanted it done. Now, self-determination means running my own life and directing my own personal care assistants on how best to assist me in my personal care.”(2001)

As shown in the literature, self-determination will be expressed and experienced differently by each individual based on a variety of factors, including skills, opportunities to make and carry-out decisions, self-concept, and positive efficacy. The system that makes supports and services available to people with disabilities plays a huge, often unperceived, role in people with developmental disabilities having true opportunities to achieve, and reap both the motivational and empowering benefits that come with true self-determination.

Table 3: Support Models and CPP table

This table reviews major categories of support models currently used in the field with respect to the extent to which they are consistent with the values of choice, participation and purpose and the extent to which choice, participation and purpose either improve outcomes for that service approach or interfere with obtaining outcomes through that approach. Choice, participation and purpose are extrinsic values that should be adhered to in any instance except those where they can be shown to be directly detrimental and perhaps even then.

- Column 1, Support Models – These are support models commonly in use in the field
- Column 2, Conceptual Support – This rates the extent to which the service approach is supportive of the values of choice, participation and purpose.
- Column 3, Emphasis Improving Outcomes –This rates the extent to which a greater emphasis on choice, participation and purpose has been shown to improve outcomes within this particular support model.

- Column 4, Emphasis Interferes with Outcomes – This rates the extent to which there is evidence that an emphasis on choice, participation and purpose will interfere with this particular support model being effective in producing the desired outcomes.

| <i>Support models</i> | <i>Conceptual Support for Values of Choice, Participation and Purpose(CPP)</i> | <i>Evidence that CPP emphasis improves outcomes from model</i> | <i>Evidence that CPP emphasis interferes with outcomes from model</i> |
|--|---|---|--|
| Person-centered Planning | Embodies the values of CPP | Ample qualitative and individual case studies literature | None |
| Self-Advocacy | Embodies the values of CPP | Qualitative research | None |
| Micro boards/Fiscal Intermediary/ Individual Budgets | Enables people/families to control resources | Individual case studies recorded in literature | None |
| Support Brokers/Support Coordination/ Independent Service Coordination | Very high support for choice and participation | Longitudinal study of Robert Wood Johnson Project | None |
| Positive Behavior Support | Embodies values of CPP | Quantitative research | None |
| Supported Living | Very high support for purpose | Quantitative research and qualitative research | None |
| Alternatives to Guardianship | Enhances CPP | Descriptive literature | None |
| Assistive Technology | Enhances CPP | Quantitative research | None |
| Community Membership | Very high for participation and purpose | Description of program models | None |

2E. Evidence Related Specifically to Youth: Resilience

The term “resilience” (defined as the capacity to work through and gain flexible strength despite great adversity) has received much attention in research on youth services. Evidence for the importance of resilience supports directly the constructs of self-determination and person-centered growth. Although recent summaries (Fraser & Galinsky, 1999) have noted that there remains much work to be done, substantial empirically valid research supports the concept of resilience and gives direction to our constructs.

Resilience literature has consistently stressed that individual’s facing adversity often do better than might be thought given the problem’s faced (Barnard, 1994; Bleuler, 1978; Garbarino et al., 1992; Matsen, 1994; Rutter, 1979; Valliant, 1993; Wolin & Wolin, 1995; Waller, 2001). A series of protective factors has been identified; many expressed as such individual characteristics as self-efficacy, self-worth, hopefulness, and a sense of purpose or direction (Waller, 2001). Of particular importance to this document, research also has documented family, community, and cultural factors as partially predictive of favorable adjustments (Benard, 1991; Felix-Ortiz & Newcomb, 1995; Garnezy, 1991; Kirby & Fraser, 1997; Miller, 1999; Miller & MacIntosh,

1999; Rutter, 1987). Resilience also has been applied to families (Walsh, 1998), organizations, (Kurzman & Akabas, 1993) and communities (Saleebey, 1997).

Evidence supporting the concept of resilience and the positive role of families, organizations, culture, and community represents some of the strongest evidence for the idea of self-determination in general. Current evidence supporting the concept of resilience includes both prospective designs examining many different factors (Hawkins et al., 1992; Matsen et al., 1999; Latimer et al., 2000) and narrative accounts (White & Epston, 1989; Margolis, Kilpatrick & Mooney, 2000).

Based on the evidence, resilience is a concept applicable to youth and adults that include a variety of positive responses to adversity. For the current document, self-determination and person-centered growth might be understood as practice constructs based on activating, and helping to create an environment for, individual resilience. By enhancing opportunities for self-determination to promote positive individual characteristics, and including families, organizations, communities, and cultural competence in our practice, we foster individual growth and resilience.

SECTION 3.

CROSS CONNECTIONS – ADDRESSING THE FEARS



SECTION 3. CROSS CONNECTIONS – ADDRESSING THE FEARS

3A. Concerns about Self-Determination as it Relates to Substance Abuse

The phrase “self-determination” and even the term “choice” are worrisome to some in the addiction treatment field. Addiction is a chronic and progressive disease process that temporarily robs people of the ability to make and carry out sound, rational choices in their best interest. Since a symptom of addiction is loss of control over decisions regarding use of the substance of choice, it is easy to mistake loss of control as self-determined decision-making. Additionally, there is a concern that people with addictions will seek out unproven treatment methods that might do more harm than good. The overwhelming desire to return to controlled use, a characteristic of addiction, is the reason a “controlled use” treatment approach is so attractive to the individual with an addiction problem. However, even the strongest proponents of a “controlled use” approach agree this treatment strategy only works with people who have not crossed that line into addictive use. Personal and professional experience tells us that if a person crosses that line from use or abuse to dependence they can never return to controlled use and attempting to do so could lead to death. People with addictions initially need others to help them make the right decisions. To engage in self-determination requires awareness of one’s lack of self-determination. The roles of the professional include awakening this notion, empowering the individual toward reasonable self-reliance and offering a continued network of resources for any woes that emerge. In addiction recovery self-determination means regaining the ability to make sound, rational choices in one’s best interest as opposed to one’s choices being determined by the compulsion to use that accompanies drug/alcohol addiction.

3B. Concerns about Recovery as it Relates to Developmental Disabilities

The term recovery has been controversial in developing this guideline, especially for families of persons born with a developmental disability. Their families explain that there is no “recovery” for their children, in that persons with a developmental disability are not returning to a previous level of functioning, rather, they are discovering their full potential. This situation is similar to many persons with severe mental illness who have recovered. They often say that they have not fully regained all the abilities they had prior to the onset of their illness, but rather they have gone on and developed new abilities that they did not have earlier in life, and for them recovery has been going on to discover their full potential. Advocates for the developmentally disabled have worked hard to reject the concept of developmental disability being a disease and have fought against their family members being viewed and treated as sick. People in the more advanced stages of recovery from mental illness and substance abuse similarly resist being defined as sick. For them, their condition is not the total definition of who they are and what they can be but just a single aspect of who they are as a multifaceted individual. It is also another aspect of their life that needs to be managed and adapted to. While it is inappropriate to speak of persons “recovering” from developmental disability they, like persons with mental illness or substance abuse, are recovering from the trauma experienced as a result of:

- Inappropriate supports and interventions
- Negative professional attitudes
- Lack of appropriate helping skills of professionals
- Devaluing and disempowering programs, practices, and environments
- Lack of enriching opportunities
- Stigma and discrimination in the community

3C. Family Concerns about Self-Determination in Mental Illness

The term “self-determination” is worrisome to some family members of persons with mental illness who have experienced periods of time when their loved one was so impacted by their mental illness that they persisted in making decisions that endangered themselves or others or refusing offered treatments and services that were likely to benefit them. Many family members who have had this experience question the wisdom of legal changes in the sixties or seventies that did away with the standard that allowed care to be forced upon a person if it was felt to be in the persons best interest or there was a “need for treatment” and replaced it with a standard requiring a finding of dangerousness. All states have mechanisms in place to hospitalize persons against their will and most states have mechanisms to provide people with treatment including medication against their will. On the surface this process of non-voluntary treatment hardly seems like self-determination. However, almost all consumer advocates support the view that persons need to be protected when their illness makes them dangerous to themselves or others and that some severely ill persons require guardians to protect their own best interests. In most cases it is apparent that at this point the consumer with mental illness is determined as opposed to self-determined. Thus when people are in the early stages of learning about how to manage their illness themselves, or are being severely impacted by their illness, self-determination may not be an achievable goal. However, as a consumer learns more about their illness and becomes better able to manage it themselves, self-determination rapidly becomes not only a possibility but a necessity for further progress. It is not possible to make decisions for oneself and take responsibility for those decisions without having the opportunity for self-determination. Self-determination is a necessary component of recovery from mental illness.

3D. Consumer Concerns about Recovery in Mental Illness

Refusal of treatment options are frequently seen as non-compliance by family members and providers regardless of the consumer’s mental status, knowledge of his or her illness, or reasons for refusal. While there are times when involuntary hospitalization and treatment is the only option available, there is concern that what constitutes “dangerousness” is too subjective and findings may be made based on history rather than current circumstances. Although there are mechanisms in place to allow the consumer to participate in the determination process, there is a concern that those who are capable of participating may not be taken seriously when speaking on their own behalf. Therefore, the act of refusal in and of itself may be judged to constitute a danger, and the consumer may then be unnecessarily forced to submit to involuntary treatment. These concerns primarily center on the enactment of temporary evaluative admissions during which time the consumer may not be aware of his or her rights to advocacy, thus undermining the consumer’s self-determination.

All too often, being stricken with a severe mental illness means losing your ability to work and with it your ability to support yourself and obtain healthcare. Due to the stigma against mental illness, persons disabled by it have greater difficulty obtaining disability entitlements than persons with physical or developmental disabilities. Many persons disabled by mental illness have experienced many months of poverty while waiting for numerous evaluations, appeals, and hearings before finally being “awarded” their disability entitlements. Often this provides the economic basis for them to begin their paths to recovery by providing basic necessities of housing, food, clothing, and healthcare without which recovery cannot be achieved. When a

person with mental illness has recovered to the point where they can again get and hold a paying job, often those initial entry-level jobs provide less or little more than their disability income and usually do not provide equivalent healthcare benefits, especially in the area of mental health treatment. This creates a very real obstacle to the recovering person who is forced to choose between limiting their own recovery by not working in order to protect their ability to support themselves and get the treatment they need versus taking a job that in a short time terminates their disability entitlements while knowing full well that if they were to get sick again, it could again take months to years to regain that security.

3E. Family Concerns about Self-Determination in Developmental Disability

It is normal in all families, whether they contain a disabled family member or not, to have situations arise where the decisions of one family member are objectionable and upsetting to other family members. Common areas of disagreement include money management, choice of friends, religious practices, and choices around romance and sexuality. The available literature on self-determination focuses primarily on consumer control of public funding in the purchase of services. However, its underpinning concepts of control and autonomy raise questions and expectations around self-determination in these more personal areas.

Families report having a number of fears about self-determination including:

1. Fears of “letting go” and allowing the individual with developmental disabilities to make and learn from mistakes
2. Fear of harm or exploitation by the system or society at large
3. Inability to trust others/society to care for and about loved one
4. Fear of failure or not believing the person has the abilities to be self-determined
5. Fears about what will happen to their loved one when they are gone

It is difficult for the family to fully embrace the role of being family without being faced with the conflict of approving a decision that they disagree with or by disagreeing decreasing the disabled persons autonomy and control within their own lives. If developmentally disabled adults really are to have the same rights as other citizens that at times will include the right to anger, frighten, or disappoint their families as a result of their choices.

SECTION 4: RELEVANT CONCEPTS FROM DMH AND CONSUMER ORGANIZATIONS



SECTION 4: RELEVANT CONCEPTS FROM DMH AND CONSUMER ORGANIZATIONS

Four documents are reported in this section:

1. Vision and Value Statement for the Department of Mental Health
2. The Report of the Consumer Workgroup on Recovery, written and prepared by consumers and advocates of mental health services for the CPS State Advisory Council (SAC), December, 1998, and
3. Show Me Change: Building a Participant-Driven System for Missourians with Developmental Disabilities, written and prepared by members of the Missouri Customer Leadership Initiative (consumers, family members, and advocates of developmental disabilities services), August, 1998 for the Missouri Planning Council for Development Disabilities (MPCDD)
4. Essential Treatment Principles from DMH Core Rules for Substance Abuse and Mental Health Programs

Each document stresses the common themes of consumer involvement in the development, planning, and implementation of services, and the promotion of values, acceptance, and respect. The following are summaries of guiding principles from each document.

4A. Vision and Value Statement for the Department of Mental Health

Our Vision

Working side by side with individuals, families, agencies, and diverse communities, the Department of Mental Health establishes philosophy, policies, standards, and quality outcomes for prevention, education, habilitation, rehabilitation, and treatment for Missourians challenged by mental illness, substance abuse/addiction, and developmental disabilities.

Values

Full community membership

Access

Individualized Services and Supports

Cultural Diversity

Dignity, Self-worth, and Individual Rights

Prevention and Early Intervention

Excellence

Valued workers

Competence

4B. Report of the Consumer Workgroup on Recovery

Defining Recovery: “Recovery is a universal human experience that maximizes people’s abilities to live self-directed lives while minimizing the impact of illness or emotional distress.”

- Recovery is based on hope: without it people do not believe in their own ability to recover and may not be motivated to achieve it.
- Recovery begins with the consumer’s current reality and current needs and extends through the individual’s achievement of self-directed goals from a variety of options.

- People need to be presented with multiple opportunities to recover.
- There are many paths to recovery, and recovery can be expected to look different for every individual.

The workgroup focused on five broad themes and examined the changes in policies, processes, attitudes and services that would need to take place within DMH, and its providers, and with consumers. Here is a summary of each theme.

Recovery Essential One: Promoting Values, Acceptance and Respect

“A recovery focused system of care reflects a belief that individuals diagnosed with serious mental illness can change, grow, and become self-directed, productive community members when they are accepted and treated with respect.”

Recovery Essential Two: Consumer Involvement

“A recovery focused system of care provides numerous opportunities for meaningful and effective consumer involvement in the design, implementation, monitoring, and evaluation of mental health services.”

Recovery Essential Three: Addition and Enhancements to the System of Care

“A recovery focused system of care includes policies, processes, and services which promote recovery and are developed collaboratively with consumers.”

Recovery Essential Four: Training, Education, and Skill Building

“A recovery focused system of care provides the training, education, and skill building needed by consumers, DMH employees, and provider agency staff to foster consumer recovery.”

Recovery Essential Five: Evaluation and Outcomes

“A recovery focused system of care evaluates the services it delivers for effectiveness, efficiency, consumer satisfaction, and fidelity to the principles and best practices of recovery.”

4C. Show Me Change Document

Overarching Core Principle: “Resources for supports in the State of Missouri must be allocated and expended from a person-centered perspective rather than a provider-centered perspective. Individuals must be in control of their allocated resources for services and supports and how they are delivered.”

Beyond that core principle, the workgroup developed a number of guiding principles that should apply for people who are eligible for developmental disability services and grouped these principles into five categories. What follows is a summary of each.

Guiding Principle 1: Community Membership

- All people with developmental disabilities belong in their community.
- Community inclusion is the basis of the services and supports that people receive.
- People with developmental disabilities have contributions to make in our communities that are equal in worth and value to those of other citizens.

- People with developmental disabilities have the same opportunity as other citizens to live in homes of their own, by themselves, with their family, or with friends of their choice.
- People with developmental disabilities have the opportunity – as do other citizens – to find and hold competitive jobs and/or otherwise contribute to the community.
- The system promotes the use of community resources, and, in so doing, builds community capacity.

Guiding Principle 2: Self-determination

- People with developmental disabilities and their family members have options in areas of services and supports.
- People with developmental disabilities are informed of the variety of options, as well as the benefits and risks associated with the choices they make.
- People with developmental disabilities have the opportunity, with support as needed from those who care about them, to make choices and decisions about their every day lives.
- Individuals have control over their allocated resources.

Guiding Principle 3: Rights

- People with developmental disabilities have the same rights and responsibilities as other citizens, including the opportunity and responsibility to direct their own lives.
- People with developmental disabilities are listened to and treated as equally as other citizens without assumptions based on their disabilities.
- People are not discriminated against due to cultural or ethnic differences.
- Services and supports are delivered in ways that recognize the centrality of the family in the lives of individuals with developmental disabilities.
- Individuals have a right to grieve any decision or process that affects their life.

Guiding Principle 4: Meeting Basic Needs

- The system is responsive to individual needs, providing help when and in the manner that people need assistance.
- People with developmental disabilities, family members, and others have peace of mind that services and supports are reliable, both today and for the future.
- Individuals have personal security in their everyday lives.

Guiding Principle 5: Systems Management

- There is an ethical responsibility to provide services in accord with these principles and “choice” shall not be used as a reason for shirking that responsibility.
- Services and supports are accessible and easy to use.
- Services and supports nurture the family structure, fostering and enhancing family unity.
- Ethnic and cultural differences are recognized, valued, and included in designing services and supports to fit individual needs.
- The system is an active partner with people with developmental disabilities and families by providing helpful and accurate information about choices.
- The system shall maintain effective oversight to ensure that individual rights are honored.
- There is a grievance process available to address complaints without retribution.

- People with developmental disabilities and their family members are informed, active, and equal partners in policy making.
- The system promotes cost-effectiveness, and any savings are reinvested in services and supports.

4.D Essential Treatment Principles from DMH Core Rules for Substance Abuse and Mental Health Programs 9 CSR 10-7.010 Treatment Principles and Outcomes.

(4) Essential Treatment Principle—Therapeutic Alliance

- (A) The organization shall promote initial attendance, engagement and development of an ongoing therapeutic alliance by—
1. Treating people with respect and dignity;
 2. Enhancing motivation and self-direction through identification of meaningful goals that establish positive expectations;
 3. Working with other sources (such as family, guardian or courts) to promote the individual's participation;
 4. Addressing barriers to treatment;
 5. Providing consumer and family education to promote understanding of services and supports in relationship to individual functioning or symptoms and to promote understanding of individual responsibilities in the process;
 6. Encouraging individuals to assume an active role in developing and achieving productive goals; and
 7. Delivering services in a manner that is responsive to each individual's age, cultural background, gender, language and communication skills, and other factors, as indicated.
- (B) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators of a therapeutic alliance can include, but are not limited to, the following:
1. Convenient hours of operation consistent with the needs and schedules of persons served;
 2. Geographic accessibility including transportation arrangements, as needed;
 3. Rate of attendance at scheduled services;
 4. Individuals consistently reporting that staff listen to and understand them;
 5. Treatment dropout rate;
 6. Rate of successfully completing treatment goals and/or the treatment episode; and
 7. Consumer satisfaction and feedback.

(5) Essential Treatment Principle— Individualized Treatment

- (A) Services and supports shall be individualized in accordance with the needs and situation of each individual served.
- (B) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement

of this essential treatment principle. Indicators can include, but are not limited to, the following:

1. There is variability in the type and amount of services that individuals receive, consistent with their needs, goals and progress;
2. There is variability in the length of stay for individuals to successfully complete a level of care or treatment episode, consistent with their severity of need and treatment progress;
3. In structured and intensive levels of care, group education/counseling sessions are available to deal with special therapeutic issues applicable to some, but not all, individuals;
4. Services on a one-to-one basis between an individual served and a staff member (such as individual counseling and community support) are routinely available and scheduled, as needed; and
5. Individuals consistently report that program staffs are helping them to achieve their personal goals.

(6) Essential Treatment Principle—Least Restrictive Environment

- (A) Services and supports shall be provided in the most appropriate setting available, consistent with the individual's safety, protection from harm, and other designated utilization criteria.
- (B) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators can include, but are not limited to the following:
 1. Utilization rate of inpatient hospitalization and residential treatment;
 2. Length of stay for inpatient and residential treatment;
 3. Consistent use of admission/placement criteria;
 4. Distribution of individuals served among levels of care; and
 5. Consumer satisfaction and feedback.

(7) Essential Treatment Principle—Array of Services

- (A) A range of services shall be available to provide service options consistent with individual need. Emotional, mental, physical and spiritual needs shall be addressed whenever applicable.
 1. The organization has a process that determines appropriate services and ensures access to the level of care appropriate for the individual.
 2. Each individual shall be provided the least intensive and restrictive set of services, consistent with the individual's needs, progress, and other designated utilization criteria.
 3. To best ensure each individual's access to a range of services and supports within the community, the organization shall maintain effective working relationships with other community resources. Community resources include, but are not limited to, other organizations expected to make referrals to and receive referrals from the program.
 4. Assistance in accessing transportation, childcare and safe and appropriate housing shall be utilized as necessary for the individual to participate in treatment and rehabilitation services or otherwise meet recovery goals.

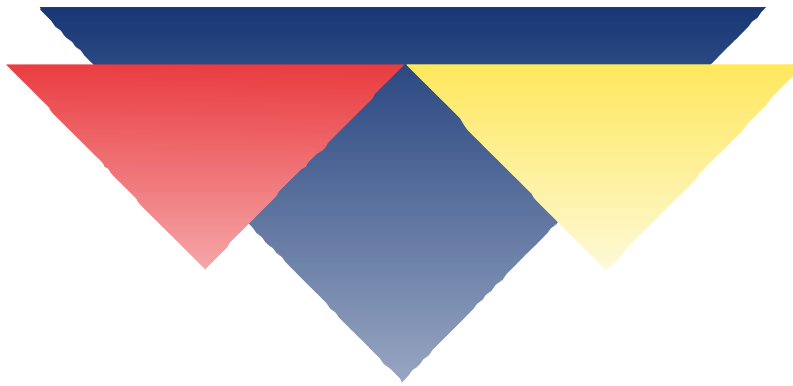
5. Assistance in accessing employment, vocational and educational resources in the community shall be offered, in accordance with the individual's recovery goals.
- (B) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators can include, but are not limited to, the following:
1. Percentages of individuals who complete inpatient or residential treatment and receive continuing services on an outpatient basis;
 2. Readmission rates to inpatient or residential treatment;
 3. Number of individuals receiving detoxification who continue treatment;
 4. Number of individuals who have progressed from more intensive to less intensive levels of care;
 5. Feedback from referral sources and other community resources; and
 6. Consumer satisfaction and feedback.
- (8) Essential Treatment Principle—Recovery**
- (A) Services shall promote the independence, responsibility, and choices of individuals.
1. An individual shall be encouraged to achieve positive social, family and occupational/educational functioning in the community to the fullest extent possible.
 2. Every effort shall be made to accommodate an individual's schedule, daily activities and responsibilities when arranging services, unless otherwise warranted by factors related to safety or protection from harm.
 3. Individuals shall be encouraged to accomplish tasks and goals in an independent manner without undue staff assistance.
- (B) Reducing the frequency and severity of symptoms and functional limitations are important for continuing recovery.
- (C) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators can include, but are not limited to, the following:
1. Measures of symptom frequency and severity;
 2. Improved functioning related to—
 - A. Occupational/educational status;
 - B. Legal situation;
 - C. Social and family relationships;
 - D. Living arrangements; and
 - E. Health and wellness;
 3. Tapering the intensity and frequency of services, consistent with individual progress; and
 4. Consumer satisfaction and feedback.
- (9) Essential Treatment Principle—Peer Support and Social Networks.**
- (A) The organization shall mobilize peer support and social networks among those individuals it serves.
1. The organization shall encourage participation in self-help groups.

2. Opportunities and resources in the community are used by individuals, to the fullest extent possible.
- (B) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators can include, but are not limited to, the following:
1. Rate of participation in community based self-help groups;
 2. Involvement with a wide range of individuals in social activities and networks (such as church, clubs, sporting activities, etc.);
 3. Open discussion of therapeutic issues in group counseling and education sessions with individuals giving constructive feedback to one another; and
 4. Consumer satisfaction and feedback.
- (10) Essential Treatment Principle—Family Involvement.**
- (A) Efforts shall be made to involve family members, whenever appropriate, in order to promote positive relationships.
1. Family ties and supports shall be encouraged in order to enrich and support recovery goals.
 2. Family members shall be routinely informed of available services, and the program shall demonstrate the ability to effectively engage family members in a recovery process.
 3. When the family situation has been marked by circumstances that may jeopardize safety (such as domestic violence, child abuse and neglect, separation and divorce, or financial and legal difficulties), family members shall be encouraged to participate in education and counseling sessions to better understand these effects and to reduce the risk of further occurrences.
- (B) Particular emphasis on family involvement shall be demonstrated by those programs serving adolescents and children.
- (C) Performance Indicators. The following are intended as examples of indicators that can be used by the department and the organization to demonstrate achievement of this essential treatment principle. Indicators can include, but are not limited to, the following:
1. Rate of family participation in treatment planning;
 2. Rate of family participation in direct services, such as family therapy;
 3. Improved family relationships;
 4. Reduction of family conflict; and
 5. Satisfaction of family members with services.

Conclusions

Based on the summaries of these documents, our workgroup is on track with our vision statement and guiding principles. These documents provide suggestions on how to implement constructs into services on the department and provider levels. They also provide guidance for consumers on what they should expect from the department and providers and how consumers can be involved in an effective manner.

SECTION 5. IMPLEMENTING THESE CONSTRUCTS INTO SERVICES



SECTION 5. IMPLEMENTING THESE CONSTRUCTS INTO SERVICES

We believe that the next steps in the change process are incremental ones. It is important to note that fluctuations in funding are opportunities to make changes towards a more efficient and effective system. Implementing choice, participation, and purpose should not be considered as an added expense, rather as an opportunity to provide better services and supports—which may or may not impact costs. The remainder of this section details our recommendations for some of these initial steps.

The system must focus on human beings not their problems through:

- Infusing a person-centered philosophy throughout DMH;
- Allocating and expending resources using a person-centered perspective rather than a provider-centered one;
- Creating the means by which the system and the consumer are mutually accountable;
- Focusing on providing services and supports aimed at maximizing life potential rather than “treating” disabilities and illness alone;
- Recognizing the partnership between the person and DMH necessary to achieving the realization of choice, participation and purpose.

Information used in creating implementation guidelines

This section presents a number of initial, incremental recommendations. Information used in creating recommendations comes from a variety of sources. Information is weighted on the following basis:

- Values and definitions provided through the mission statement (Section 1);
- Evidence from the research literature (Sections 2 and 3);
- Previous consensus statements and the DMH mission statement (Section 4);
- A series of meetings with stakeholder groups;
- Presentations by guest speakers; and
- Consensus emerged in committee weighing these factors.

Because the evidence from the research was somewhat limited, we were forced to rely on our other sources to a greater extent than we had originally anticipated.

NEXT STEP IN THE CHANGE PROCESS

This document begins the change process. To measure subsequent change, it is necessary to closely compare the current practices to our vision of choice, participation and purpose. Methods used to complete this comparison need to be based in a person-centered approach. This would include examining: (a) barriers and facilitators of access, (b) provision of supports and services, (c) relationships between persons receiving services/supports and their providers, and (d) successes and failures within the system—all from the perspective of those receiving the services. Thus, the question is not “What is in the treatment/personal plan?” but rather “How is this perceived by the person?”

We recommend that data be collected through a series of focus groups and individual interviews of persons receiving services and providers. The analysis of this data would need to weight the results from persons receiving services and providers equally, understanding the perspective of each, as well as comparing similarities and differences. These results would then be compared with actual services provided and used to prioritize recommendations for implementation and to measure future service changes and outcomes.

5A. Guidelines for Implementation in Individual Services

A. *Initial Contact*

- A1. Consumers have a right to be educated on all participation options available at initial call-in or access of website. Implementation of this includes:
 - 1. Immediate access to intake workers trained in intake and referral
 - 2. Option for immediate referrals to cultural or gender matched intake worker
 - 3. Complete information on intake process and referral opportunities
 - 4. Information on screening criteria used as a basis for referral recommendations
 - 5. Maximize choices of referrals through consumer participation
 - 6. Fewer/more direct phone transfers

B. *Assessment/Intake*

- B1. Consumers have a right to make choices regarding staff (case manager/therapist/service coordinator/physician) whenever possible, as well as a right to change these workers. Consumers should be provided with a brief sketch of providers that provide information on training, experience, skills, and interests. When choice is not available or not reasonable for some specific treatment reason, the consumer has a right to be informed as to these reasons. These choices might include:
 - 1. Being made based on gender, race, expertise matching
 - 2. Changing providers if match is not working
 - 3. Considering peer involvement/counseling as appropriate service options
- B2. Consumers have a right to have input into the assessment/intake process. Although this is not an absolute right (e.g., assessment instruments and diagnoses are required), ordering of tasks within the assessment process can be made more flexible to make this a more person-centered process.
- B3. Families have a right to provide input into the assessment process. This includes providing information relevant to the consumer, and to the consumer's ability to provide information. This is distinct based on the age of the primary consumer (child versus adult) and whether the family has legal guardian status.
 - a) Child as primary consumer/family as guardian. The child/consumer has a right to provide assessment information that needs to be considered as valid in completing the assessment process. This includes input on preferences and participation.
 - b) Adult as primary consumer. Families have a right to provide assessment information, including direct information on their role in the service process. While providers cannot reveal consumer information to families without consent, they can receive information from families without consent.

- B4. Consumers have a right to have input into their own diagnosis. This includes presentation by the clinician of all relevant information used to determine the diagnosis. Consumers have the further right to access to all materials, including reviewing specific DSM criteria. This should occur prior to formal assignment of diagnosis. In cases where the consumer feels that an inappropriate diagnosis has been assigned, they have the right to request a review by an external advocate designated by the consumer in consultation with the clinician. The formal diagnosis will be assigned by consensus among the consumer, clinician, and the advocate.
- C. *Service & Treatment Planning*
- C1. Consumers need to be valued as a part of the treatment/service coordination team. This includes:
1. Participating as part of the planning process, including goal setting, moves beyond having the consumer simply sign off on these goals, but being part of the identification, operationalization, and review.
 2. Right to have access to service/treatment plan and all assessment information. This should consist of giving the consumer a copy at completion, as well as access upon request.
- C2. Families have a right to be included in the planning process. This includes membership on the treatment/service coordination team, unless the consumer is an adult, in which case, only the consumer has a right to exclude.
- C3. Consumers have a right to have input on the type of service/treatment provided. This right should be respected unless there are compelling reasons (e.g., the service/treatment may prove physically harmful to the consumer) that consumer input should not be given. In this case, the reasoning needs to be made clear to the consumer.
1. This includes resource allocation being from a person-centered perspective, rather than a provider-centered perspective. Individuals must be in control of planning the allocation of their resources for services and supports and how they are delivered. The service system should not dictate the plan; the person should dictate the plan.
- D. *Service/Treatment Delivery*
- D1. Consumers have a right for advocates to maximize opportunities for choice of services and participation in service/treatment decision-making throughout the service/treatment process.
- D2. Consumers have the right to the minimal level of guardianship possible, including no guardianship where appropriate. Guardianships need to be limited to specific areas to the extent possible, rather than generic guardianships of the whole. Consumers have a right to input in the choice of their own guardian. Further, guardianships need to be reviewed periodically and adjusted to increasing competence.
- D3. Consumers have a right to receive best service options—regardless of where that service is offered. This includes services within the same, or across, divisions. This includes the

right to leave or return to services as the condition changes with no penalties other than natural consequences of re-application and illness process.

E. *Outcomes*

Outcomes, as conceptualized here, exist at two levels: (a) across the system, which measures population changes that are associated with services; and (b) individual, which measures achievement of goals by individuals relative to their condition. We are not advocating against examining changes in populations (e.g., sobriety for ADA clients), rather we are focusing on changes related to individuals achieving meaning and personal growth. Standardized outcomes for individuals need to be measured to provide group information but are not sufficient to promote the values expressed in this document.

E1. Outcomes for the individual should not be defined by the system but by the person. Meaning and achievement are defined by individuals.

E2. Outcomes should change as the individual changes, reflecting personal growth.

5B. Guidelines for Systems Change

a. *Creation of standards of guardianship documents presented to judges, levels of guardianship, alternatives*

By its nature, guardianship is the antithesis of self-determination, resulting in partial or total denial of the consumer's basic civil rights and liberties (Herr).

Prior to assignment of any level of guardianship, alternatives need to be explored. Alternative options can eliminate the need for guardianship and preserve the consumer's rights and dignity. Such options may include:

- Advance directives for health and psychiatric care
- Durable powers of attorney for health and psychiatric decisions
- Representative payees and trustees for financial management
- A mandatory co-signer on bank accounts and contracts
- Person-centered planning
- Supported training for self-advocacy

When guardianship appears to be inevitable, considerable flexibility may still be used at the court's discretion, as demonstrated in Wisconsin with legislation that states in part,

"The court shall make a specific finding as to which legal rights the person is competent to exercise. Such rights include but are not limited to the right to vote, to marry, to obtain a motor vehicle operator's license or other state license, to hold or convey property and the right to contract (Wisconsin s. 880.33(3))."

The assessment of need for guardianship should be performed with the least restrictive application possible keeping in mind the need to protect the person's rights and liberties to the fullest extent possible and with the understanding that the assignment of guardianship automatically confers upon the ward the label of "incompetent." To that end, plenary guardianship should be avoided whenever possible in favor of person-specific, needs-based supervision (Herr). The consumer should have the right to accept or reject the proposed guardian. Corporate and public agency guardianship applications should be disallowed in favor

of individual representative supervision (Nerney). The preferences of the consumer must be taken into account, as should the possibility of reducing mandated supervision through less restrictive alternatives such as those listed above. The possibility of limited and temporary guardianship should be explored. Period review is necessary to prevent abuse, determine guardian authority, and reassess need (Herr, S. 1999, Hoyle, D. and Harris, K. 2001).

b. Providers need to be trained in advocacy

People who work as direct support/service providers fulfill many roles beyond their basic job description. One of these is the role of advocate. Being an advocate for someone involves supporting him or her, arguing for him or her, and sometimes speaking for him or her. Helping the people they serve be self-advocates may involve providing transportation, encouraging participation, and promoting learning opportunities (Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, 2002). In some situations, providers may also feel tension between the ideals of the profession and its practice. There are numerous pressures coming from organizations, government, social policy, and societal prejudice that can shift the focus away from the people we serve. This affects the partnership, respect, and trust that must exist in a helping relationship. Advocacy is needed when the needs of the system override those of the individuals, or when individual preferences, needs, or gifts are neglected for other reasons (Developmental Disabilities Council of New Hampshire, no date; National Alliance for Direct Support Professionals, 2001).

Training and continuing education offered to providers should include topics related to advocacy and attitudes. Our values and attitudes can influence how persons are perceived. DMH consumers have had to fight negative stereotypes and attitudes both within the service system and in their communities. Over the years, various labels have been used to classify people with disabilities and people with substance use disorders. These labels tend to have negative meanings and images and have caused people to be treated according to their diagnosis instead of as individuals. As a result, expectations have been lowered, lifestyles have been restricted, programs have been intrusive, and people have been isolated.

It is important for providers to know that their attitudes may influence how the people they serve are supported in the community. To support others in becoming self-determined, providers must be well grounded in listening to and understanding human behavior. Understanding the many factors, which influence human behavior and the way that behavior generally tends to present itself, will guide understanding of others. The learner can begin to listen not only to words and body language, but also to actual behaviors themselves and the message behind those behaviors. Many of us have had the opportunity to discover that the people we serve can contribute to our lives as friends, co-workers, teachers, and neighbors. Higher expectations are created once we get to know people as “people first”. Our attention shifts from the person’s deficits to what the person can contribute and accomplish. We begin to reshape our roles from caretaker to support person. We can begin to focus on choice rather than control.

c. Creation of system monitoring procedures

Key to successful implementation of the recommendations made in this document is the creation of system monitoring procedures. These need to be designed to achieve two purposes.

First, is monitoring implementation and system change from a system that is likely to be resistant at all levels. This includes both oversights into initial change (are agencies and practitioners creating new systems in response to the recommendations) and into compliance (are they complying with new protocols and requirements). Specifying all the intricacies of meeting these goals is beyond the scope of the current document. However, our recommendation is that monitoring includes not just standard reporting by agencies (documenting compliance in service records and reports submitted to the DMH), but also assertive periodic reviews conducted by teams including consumers, families, and outside professionals. Further, we recommend that these teams have power to make reports directly to DMH administrators, as well as making them publicly available to consumers.

Second, is examining the impact of these changes on outcomes. We recommend the use of both quantitative methods (e.g., pre- and post-testing of significant outcomes) and qualitative interviews (e.g., focus groups or narrative interviews of consumers). It is not enough to use either method separately. Further, we recommend that outcomes research be used to specify essential elements of choice, participation and purpose, and use these to guide further implementation. In this manner, these constructs become incorporated as part of evidence-based practice, and the confirmation of deficiency in creating this guideline can be used to strengthen it.

d. Community education

The word “community” is used several times throughout this document either by itself or with other terms, such as community based services, community involvement, community support, and community membership. You cannot talk about choice, participation and purpose without mentioning community. People served by DMH want to live, be supported, and receive services in their own communities. However, consumers still face negative stereotypes and stigma in their daily lives. Education is still needed for the general public to dispel these myths so that our consumers can fully participate in their communities and not be segregated.

When people are segregated from the community, a message is sent to other community members that the segregated person is different, that they cannot function in the community, and that they require some type of special treatment. In the extreme, this can create the idea that these different people are dangerous. At a minimum, it reinforces the idea that they are not like everyone else.

Everyone providing services and supports for DMH consumers must make a conscious choice to educate the general public about recovery and self-determination. They must seize the opportunity to be good role models in their own communities. Those in the community who meet people with disabilities see not only the person, but also how we feel about and respond to them. If we are interested in what the person has to say, others may model this interaction or believe the person has value.

People First language plays an important role in changing negative stereotypes. People First language puts the person before the disability. It describes what the person has, not what the person is (e.g., a person with mental illness). Using People First language means avoiding words or phrases that evoke pity or fear, or that have negative connotations. Language is powerful. When we misuse words, we reinforce the barriers created by negative and stereotypical attitudes.

If DMH consumers are to be included in all aspects of our communities, we must talk about them, and they must talk about themselves, in positive terms.

5C. Implementation within Individual Divisions

a. Recommendations for Implementation in MR/DD

1. The values of self-determination along with the quality outcomes should be the measure by which the supports and services provided by the Division of MR/DD are planned and evaluated. These values should become the stated values of the division and influence policy and service delivery. (Preserving the enhancement component of the Division's quality frameworks)
2. Olmstead – choice and the money do follow the person. Community capacity needs to be developed to support people in the community.
3. DMH and its providers should no longer seek or be supportive of others seeking full guardianship. DMH and its providers should only seek or support limited focal guardianship of specific areas when absolutely necessary.
4. Individuals who use supports and services should be provided opportunities to impact the decision making process in the Division regarding allocation of resources/program practices. Individual Regional Centers and habilitation centers should consult with people who use supports and services in their region. (e.g., MOCAN volunteers)
5. Consumer and family control of resource-policy changes that put control and allocation of resources available for community services and supports in the hands of those who receive the services
6. Creation of a statewide parent-to-parent support network
7. Creation of Microboards/Fiscal Intermediary
8. Person-centered planning – People who use supports and services should be trained and supported to develop their own person-centered plans.
9. Families should be trained to develop plans with their sons or daughters who have disabilities.
10. Waiver amended to include employment services
11. Developing Direct Support Professionals statewide organization – chapters in each region. Improved direct support staff training policy changes related to the training of those who receive the services (focus on supporting people with disabilities to obtain lifestyles of their own choosing in their communities).
12. Training: Build capacity for Community Support Network-Training on Self-Determination. Ultimately the training should be available in each region through a training team.
13. Organizational change initiatives: Provide management training and consultation to support community agencies to “retool” their approach to providing services to one that is based on upon a paradigm of person-centered support
14. Community education regarding values of self-determination
15. People with developmental disabilities doing training for professionals
16. Make partners in policy making more accessible statewide, happening on a more frequent basis.

b. Recommendations for Implementation in ADA

1. The DMH Core Rules for CPS and ADA programs (9CSR 10-7.010 Treatment Principles and Outcomes) enhance consumer choice, participation and recovery.
 - a. Educate consumers and providers about these treatment principles and outcomes.
 - b. Monitor program compliance with these outcomes.
2. Educate families and other interested parties that adults with alcohol and other drug abuse and dependence have the right to make their own decisions including the right to experience the natural consequences of those decisions.
3. Educate courts and other state departments and divisions regarding;
 - a. Consumer rights
 - b. Efficacy of mandated treatment
 - c. Level of care decisions should be therapeutic not punitive.
 - d. Encourage “drug court” model for criminal justice referrals.
4. Encourage consumer roles of service within addiction prevention and treatment systems by making it clear how clients transition from the “impaired” role to service roles such as;
 - a. 12 Step service work
 - b. Peer support within the treatment program
 - c. Speakers/ Volunteers/Advocacy work
 - d. Paid staff positions with in treatment and prevention programs
 - e. Membership on boards, committees and workgroups
5. Individualizing treatment also means a commitment to flexible lengths of time in a level of care, and flexible use of service packages.
6. Encourage exploration of different pathways to recovery.
7. Don’t stop treatment when a relapse occurs. Create a relapse management level of service.
8. Theories are not as important as the client’s individuality and the quality of the Therapeutic Relationship. (The Heart and Soul of Change, 1999 APA press) Service and Treatment Providers must establish
 - a. A warm, welcoming initial contact;
 - b. An empathic, hopeful, continuous treatment relationship, which provides integrated treatment and coordination of care through the course of multiple treatment episodes; and
 - c. Constant expectation and hope that recovery will be achieved.(The Center for Mental Health Services Managed Care Initiative, Kenneth Minkoff MD, Panel Chair, January 1998)
9. Continue to create consumer oriented DMH public Internet sites that allow consumers to have a choice in the way they obtain information, receive consultation, obtain referral, and participate in online peer support.

c. Recommendations for Implementation in CPS

1. Training. The Division should provide ongoing training on the values of choice, participation and purpose and the concepts of recovery and self-determination as they relate to persons with mental illness. This information should be provided to consumers and family members as soon as possible (e.g., upon admission, initial diagnosis, CPR programs, etc.)

2. Consumers should be provided with information about available individual clinicians and case managers.
3. Whenever consumers are given a new diagnosis, and at least annually, they should also be given a list of the diagnostic criteria for that diagnosis and be offered an opportunity to discuss the criteria with the diagnostician.
4. Peer-counseling warm lines should be available to all DMH-CPS consumers. All consumers should periodically receive information on how to contact a peer-counseling warm line.
5. All CPS/DMH consumers should have access to a peer support group.
6. A billing unit for supported employment should be made available provided that individuals with specialized training for whom that is their sole job duty do the service. This specialist should be an integral part of the case management team. This is applicable only for competitive community employment of a non-transitional nature and is not applicable for prevocational training.
7. A billing unit supporting the acquisition and services necessary to train and care for mental health service animals should be implemented.
8. DMH and its providers should no longer seek or be supportive of others seeking full guardianship. DMH and its providers should only seek or support limited focal guardianship of specific areas when absolutely necessary.
9. CPS case management rules should require documentation that the consumer is regularly provided with additional educational materials regarding their illness, recovery philosophy and programs, possible treatments, and symptom self-management.
10. CPS should adopt MRDD's method of person-centered planning. Person-centered planning should be paired with training in stages of change in tailoring treatment plans. This would assure a much more person-oriented and centered treatment plan.
11. The DMH Core Rules for CPS and ADA programs (9CSR 10-7.010 Treatment Principles and Outcomes) enhance consumer choice, participation and Recovery.
 - a. Educate consumers and providers about these treatment principles and outcomes.
 - b. Monitor program compliance with these outcomes.
12. Continue to create consumer-oriented DMH public Internet sites that allow consumers to have choice in the way they obtain information, receive consultation, obtain referral, and participate in online peer support.

Special Issues:

1. Mandated treatment (outpatient commitment, forensic, drug and mental health court diversion programs)

NOTE: Recommendations here are drawn from a variety of sources already discussed. Where the language exists within these documents, we have chosen to directly use this language.

SECTION 6. CONCLUSIONS



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A. The weight of evidence

The literature in all of the three areas: Self-Determination in Developmental Disabilities, Recovery from Substance Abuse, and Recovery from Mental Illness is notable for a nearly complete lack of large scale, well-designed, empirical studies with adequate control groups to support the individual concepts or specific interventions supportive of the concepts. However, in all three areas there is broad, consistent, and compelling expert consensus supporting the meaningfulness of the concepts and individual supports and interventions that facilitate their achievements. The majority of the interventions discussed are also supported by a few controlled studies and a large number of uncontrolled program outcome reports.

In our re-conceptualization of the task of literature, we searched for specific evidence that any of the concepts captured by these terms was counter indicated. Our conclusion is that, although there are cautionary notes sounded across all areas, the evidence itself is either supportive of the inclusion of these concepts, or at worst silent. While we have devoted an entire chapter to addressing fears and issues related to choice, participation, and purpose, the lack of evidence for limiting the inclusions of these concepts has led us to conclude that there exists no reason for not implementing the recommendations on a broad basis.

B. Concept Congruence

Recovery and Self-Determination highly value, support, and recognize the importance of choice and participation in people's lives. Regarding the core value of purpose Recovery from Substance Abuse and Mental Illness speak to it only in the very latest stages. Self-Determination speaks to the principle of purpose as a core value.

Contrasting Recovery and Self-Determination, Recovery from Substance Abuse and Mental Illness presents itself as a process that an individual undergoes over time whereas self-determination is presented as an opportunity one either has or does not have. Recovery presents itself as more an internal personal change than external system change, while self-determination is focused on both making a change in the service system and within the individual himself. Recovery identifies some of the problems and deficits as occurring within the individual in the form of disease or symptoms, whereas self-determination identifies problems and areas needing change in the service system not in the individual. Self-Determination includes the specific strategy of consumer control of fiscal resources and funding decisions as a way of achieving its objectives, whereas recovery does not specifically identify a particular intervention or strategy as key. Recovery includes an emphasis on independence and health that is not an explicitly stated part of self-determination. Self-Determination makes much more detailed and explicit statements about the importance of a person having control in their lives than recovery. The only difference in the concept that is mutually exclusive is around the issue of whether or not the individual has problems that they need to change or new skills they need to acquire within themselves.

Table 4 – Concept Comparisons

| RECOVERY | SELF-DETERMINATION |
|--|--|
| Choice and participation are essential core concepts | Choice, participation and purpose are essential core concepts |
| Purpose becomes important later in recovery process | Purpose is important through the self-determination process |
| An internal process of change | An internal process of change and an external relationship to the service system |
| No specific strategy | Specifies consumer control of system resources |
| Emphasizes independence and health | Emphasizes control of ones life |
| Identifies need for changes in service system | Identifies need for changes in service system |
| SA and MI are diseases | DD is not a disease |
| SA and MI cause problems and deficits | Societal response to DD causes problems and deficits |

BIBLIOGRAPHY



BIBLIOGRAPHY

Abery, B. (1993). A conceptual framework for enhancing self-determination. In M. Hayden & B. Abery (Eds.), *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities* (pp. 345-380). Baltimore: Brookes.

Addington, J; McCleary, L; Munroe, B., (1998) Relationship between cognitive and social dysfunction in schizophrenia. *Schizophrenia-Research*. Nov; Vol 34(1-2): 59-66.

Addington, J; el-Guebaly, N. (1998) Group treatment for substance abuse in schizophrenia. *Canadian-Journal-of-Psychiatry*. Oct; Vol 43(8): 843-845.

Adrian, M. (2001). Do treatments and other interventions work? Some critical issues. *Substance Use and Misuse*, 36, 1759-1780.

Adrian, M. & Hyg, M. (2001). Do treatments and other interventions work? Some critical issues. *Substance Use & Misuse*, 36, 1759-1780.

Agran, M. (1997). Student-directed learning: Teaching self-determination skills. Pacific Grove, CA: Brooks/Cole.

American with Disabilities Act (ADA) of 1990 (P.L.101-336).

American Society of Addiction Medicine (1997). *Relationship between treatment and self help: A joint statement of the American Society of Addiction Medicine, Inc. and the American Academy of Addiction Psychiatry*, (<http://www.asam.org/ppol/aaap.htm>).

Anderson CM, Reiss DJ, Hogarty GE. (1986) *Schizophrenia and the Family: A Practitioner's Guide to Psychoeducation and Management*. New York: The Guilford Press.

Anthony, William. (1993). Recovery From Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990's. *Psychosocial Rehabilitation Journal*, 16(4) 11-23.

Anthony, W. A. (1991). Recovery from mental illness: The new vision of services researchers. *Innovations and Research*, 1 (1), 13-14.

Anthony, William. (2000). A Recovery-Oriented Service System: Setting Some System Level Standards. *Psychiatric Rehabilitation Journal*, 24(2) 159-168.

Baer, J. S., Kivlahan, D., R., & Donovan, D. M. (1999). Integrating skills training and motivational therapies: Implications for the treatment of substance dependence. *Journal of Substance Abuse Treatment*, 17, 15-23.

Baker, D.J., Horner, R.H., Sappington, G., Ard, W.R, (2000). A Response to Wehmeyer (1999) and a Challenge to the Field Regarding Self-Determination. Focus on Autism & Other Developmental Disabilities, Fall2000, Vol. 15, Issue 3, p.154, 3p.

Banks, B., Charleston, S., et al., (2001) Workplace supports, job performance, and integration outcomes for people with psychiatric disabilities. *Psychiatric-Rehabilitation-Journal*. Vol 24(4): 389-396.

Bambara, L.M., Cole, C.L., & Kroger, F. (1998). Translating self-determination concepts into support for adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 23, 17-26.

Barak, Y., Savorai, O. et al (2001) Animal-assisted therapy for elderly schizophrenic patients: A one-year controlled trial. *American-Journal-of-Geriatric-Psychiatry*. Vol 9(4): 439-442.

Barker, S. (1999). Therapeutic aspects of the human-companion animal interaction. *Psychiatric Times*. Vol. 16 (2).

Barker, S. B., Dawson, K.S., (1998) The effects of animal-assisted therapy on anxiety ratings of hospitalized psychiatric patients. *Psychiatric-Services*. Vol 49(6): 797-801.

Barnard, C. (1994). Resiliency: A shift in our perception? *American Journal of Family Therapy*, 22, 135-144.

Becker, D. R., Smith, J. T. et al., (2001) Fidelity of supported employment programs and employment outcomes. *Psychiatric-Services*. Vol 52(6): 834-836.

Benard, B. (1991). *Fostering resiliency in kids: Protective factors in the family, school, and community*. Portland OR: Northwest Regional Educational Laboratory.

Berg, I. K. (1995). Solution-focused brief therapy with substance abusers. In A.M. Washton (ed.) *Psychotherapy and substance abuse: A practitioner's handbook*. (pp. 223-242). New York: Guilford Press.

Bleuler, M. (1978). Different forms of childhood stress and patterns of adult psychiatric outcome. In N.S. Watt, E.J. Anthony, L.C. Wynne, & J.E. Rolfe (eds.) *Children at risk for schizophrenia: A longitudinal perspective*, 537-542. New York: Cambridge University Press.

Bolton, B., & Brookings, J. (1996). Development of a multifaceted definition of empowerment. *Rehabilitation Counseling Bulletin*, 39, 256-264.

Bond, G. R., Becker, D. R., et al, (2001). Implementing supported employment as an evidenced-based practice. *Psychiatric Services* VOL 52(3); 313-322.

Bond, G. R., Drake, R. E., et al. (1997). An update of supported employment for people with severe mental illness. *Psychiatric-Services*. Vol 48(3): 335-346.

Bowman, B. D. V. (1999) Thinking outside the box: Use of invitational counseling to promote self-determination for people with disabilities. *Mental-Retardation*. Dec; Vol 37(6): 494-496.

Brotherson, M.J., Cook, C.C., Cunconan-Lahr, R. & Wehmeyer, M.L. (1995). "Policy supporting self-determination in the environments of children with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 30 (1), 3-14.

Brown, F., Belz, P., Corsi, L., & Wenig, B. (1993). Choice diversity for people with severe disabilities. *Education and Training in Mental Retardation*, 28 (4), 318-326.

Brown, F., Gothelf, C.R., Guess, D., & Lehr, D.H., (1998). Self-determination for individuals with the most severe disabilities: Moving beyond the chimera. *Journal of the Association for Persons with Severe Handicaps*, 23 (1), 17-26.

Calsyn, R. J., Winter, J. P. & Morse, G. A. (2000). Do consumers who have a choice of treatment have better outcomes? *Community Mental Health Journal*, 36, 149-160.

Calsyn, R. J., Winter, J. P., Morse, G. A. (2000). Do consumers who have better treatment have better outcomes? *Community Mental Health Journal*, 36, 149-160.

Campbell, J.F. (1991). The consumer movement and implications for vocational rehabilitation services. *Journal of Vocational Rehabilitation*, 1 (3), 67-75.

Carpenter, K. M., Miele, G. M., & Hasin, D. S. (2002). Does motivation to change mediate the effect of DSM-IV substance use disorders on treatment utilization and substance use? *Addictive Behaviors*, 27, 207-225.

Carroll, K. M., Libby, B., Sheehan, J., & Hyland, N. (2001). Motivational interviewing to enhance treatment initiation in substance abusers: An effectiveness study. *The American Journal on Addictions*, 10, 335-339.

Center for Substance Abuse Treatment (2000, November). *Changing the conversation: Panel reports, public hearings, and participants*. U.S. Department of Health and Human Services.

Clark, R. E., Bush, P. W., (1996) A cost effective comparison of supported employment and rehabilitative day treatment. *Administration and Policy in Mental Health*. Vol. 24 (1): 63-77.

Connors, G. J., Donovan, D. M., & DiClemente, C. C. (2001). *Substance abuse treatment and the stages of change: Selecting and planning interventions*. New York: The Guildford Press.

Cornell Empowerment Group (1989). Empowerment and family support. *Networking Bulletin*, 1, 1-23.

Corrigan, P. W., Davies, F., et al., (1990) An analysis of the behavior components of psychoeducational treatment for persons with chronic mental illness. *Rehabilitation-Counseling-Bulletin*. Vol 33(3): 200-211.

Cunningham, J., Sobell, L. & Sobell, M. (1996). Are disease and other conceptions of alcohol abuse related to beliefs about outcome and recovery? *Journal of Applied Social Psychology*, 26, 773-780.

Davidson, L., Strauss, J. (1992). Sense of Self in Recovery from Severe Mental Illness. *British Journal of Medical Psychology*. (1992) 65, 131-145.

Deci, E. L. & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*, New York: Plenum.

Deci, E. L., Hodges, R., Pierson, L., & Tomassone, J. (1992). Autonomy and competence as motivational factors in students with learning disabilities and emotional handicaps. *Journal of Learning Disabilities*, 25. 457-471.

Deegan, P. (1999) Service dogs help people get back out into the community, National Empowerment Center, Inc. (<http://www.power2u.org>).

Denning, P. (2000). *Practicing Harm Reduction Psychotherapy*. New York: The Guilford Press.

deShazer, S. (1990). Brief therapy. In J. K. Zeig and W. M. Munion (Eds.) What is psychotherapy? *Contemporary perspectives* (pp.278-282). San Francisco: Jossey-Bass.

Dickerson, Faith. (1998). Strategies That Foster Empowerment. *Cognitive and Behavioral Practice*, 5, 255-275.

DiClemente, C., Bellino, L., & Neavins, T. (1999). Motivation for change and alcoholism treatment. *Alcohol Research & Health*, 23, 2, 86-92.

DiClemente, C.C., Prochaska, J.O. (1998). Toward a comprehensive transtheoretical model of change: Stages of change and addictive behaviors., *Treating Addictive Behaviors*, 2nd ed. Plenum Press.

Dilk, M. N., Bond, G. R., (1996) Meta-analytic evaluation of skills training research for individuals with severe mental illness. *Journal-of-Consulting-and-Clinical-Psychology*. Vol 64(6): 1337-1346.

Dixon L, & Lehman AF. (1995). Family interventions for schizophrenia. *Schizophrenia Bulletin*, 21, 631-643.

Dixon, L. (2000). Assertive community treatment: Twenty-five years of gold. *Psychiatric Services*, 51, 759-765.

Doane JA, Goldstein MJ, Miklowitz DJ, Falloon IRH. (1986). The impact of individual and family treatment on the affective climate of families of schizophrenics. *British Journal of Psychiatry*, 148, 279-287.

Dodd, M. H. (1997). Social model of recovery: Origin, early features, changes, and future. *Journal of Psychoactive Drugs*, 29, 133-139.

Drake, R. E., McHugo, G. J., et al, (1999). A randomized clinical trial of supported employment for inner-city patients with severe mental disorders. *Archives of General Psychiatry*. Vol. 56 (7): 627-633.

Dudley, J. (2000). Confronting Stigma within the Services System. *Social Work*, Oct.2000, Vol. 45 Issue 5, p. 449, 7p.

Duncan, Hubble, Miller 1999.

Duncan, B. L., Solovey, A. D., & Rusk, G. S. (1992). *Changing the rules: A client directed approach to therapy*. New York: The Guildford Press.

Dunn, C., DeRoo, L, & Rivara, F. (2001). The use of brief interventions adapted from motivational interviewing across behavioral domains: A systematic review. *Addiction*, 96, 1725-1742.

Falloon IRH, Boyd JL, McGill CW, Williamson M, Razani J, Moss HB, Gilderman AM, Simpson GM. (1985). Family management in the prevention of morbidity of schizophrenia. *Archives of General Psychiatry*, 42, 887-896.

Falloon IRH, Boyd JL, McGill CW, Razani J, Moss HB, Gilderman AM. (1982). Family management in the prevention of exacerbations of schizophrenia: a controlled study. *New England Journal of Medicine*, 306, 1437-1440.

Falloon IRH, McGill CW, Boyd, JL, Pederson J. (1987). Family management in the prevention of morbidity of schizophrenia: social outcome of a two-year longitudinal study. *Psychological Medicine*, 17, 59-66.

Farkas, A., Pierce, J., Zhu, S., Rosbrook, B., Gilpin, E., Berry, C., & Kaplan, R. (1996). Addiction versus stages of change models in predicting smoking cessation. *Addiction*, 91, 1271-1280.

Felix-Ortiz, M. & Newcomb, M.D. (1995). Cultural identity and drug use between Latino and Latina adolescents. In G. J. Botvin, S. Schinke, & M. A. Orlandi (eds.) *Drug abuse prevention with multiethnic youth*, 147-165. Thousand Oaks, CA: Sage Press.

Fenton, W. S., Blyler, C. R., et al., (1997) Determinants of medication compliance in schizophrenia: Empirical and clinical findings. *Schizophrenia-Bulletin*.; Vol 23(4): 637-651.

Ficker, T. C. (1998). Self-determination...Let's get a life. Keynote address at the annual meeting of The Arc of North Carolina State, Burlington, N.C.

Field, S. & Hoffman, A. (1994). Development of a model for self-determination. *Career Development for Exceptional Individuals*, 17, 159-169.

Fiorentine, R., & Anglin, D. (1997). Does increasing the opportunity for counseling increase the effectiveness of outpatient treatment? *American Journal of Drug and Alcohol Abuse*, 23, 369-382.

First International Conference on Self-Determination and Individualized Funding, Seattle, July 2000.

Fisher, D. B. (1994). Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. *Hospital and Community Psychiatry*, 45, 913-915.

Fisher, D. B. & Ahern L. (2000). Personal Assistance in Community Living: An alternative to PACT. *Ethical Human Sciences & Services*, 2, 87-92.

Fleischer, R (2002) Psychiatric advanced directives: An analysis of advance directive statutes and their application to mental health care and treatment. National Mental Health Association Toolkit on Psychiatric Advance Directives. Advocacy, Training and Technical Assistance Center of the National Association of Protection and Advocacy Systems.

Forman, R., Bovasso, G., & Woody, G. (2001). Staff beliefs about addiction treatment. *Journal of Substance Abuse Treatment*, 21, 1-9.

Fraser, M. W. & Galinsky, M. J. (1997). Toward a resilience-based model of practice. In M. Fraser (ed.) *Risk and Resilience in childhood: An ecological perspective*, 265-275. Washington DC: NASW Press.

Fraser, M.W., Richman, J. M., et al., (1999) Risk, protection, and resilience: Toward a conceptual framework for social work practice. *Social-Work-Research*.; Vol. 23(3): 131-143.

Froling, J. (1998) Service dog tasks for psychiatric service dogs. International Association of Assistance Dog Partners. February 1, 1998 (http://www.iaadp.org/psd_tasks.html).

Garbarino, J, Dubrow, N., Kostelny, K., & Pardo, C. (1992). Children in danger: *Coping with the consequences of community violence*. San Francisco CA: Josey-Bass.

Garmezy, N. (1991). Resiliency and vulnerability to adverse developmental outcomes associated with poverty. *American Behavioral Scientist*, 34, 416-430.

Gerwe, C. F. (2000). Chronic addiction relapse treatment: A study of the effectiveness of the high-risk identification and prediction treatment model. Part I. *Journal of Substance Abuse Treatment*, 19, 415-427.

Gerwe, C. F. (2000). Chronic addiction relapse treatment: A study of the effectiveness of the high-risk identification and prediction treatment model. Part II. The HRIPTM case table, case study examples and questionnaire. *Journal of Substance Abuse Treatment*, 19, 429-438.

Gerwe, C. F. (2000). Chronic addiction relapse treatment: A study of the effectiveness of the high-risk identification and prediction treatment model. Part III. Conclusion and future implications of HRIPTM research. *Journal of Substance Abuse Treatment*, 19, 439-444.

Gingerich, W. J., & Eisengart, S. (2000). Solution-focused brief therapy: A review of the outcome research. *Family Process*, 39, 477-498.

Graham, H. L. (1999). The role of dysfunctional beliefs in individuals who experience psychosis and use substances: Implications for cognitive therapy and medication adherence. *Behavioural and Cognitive Psychotherapy*, 26, 193-208.

Granfield, R. & Cloud, W. (2001). Social context and “natural recovery”: The role of social capital in the resolution of drug-associated problems. *Substance Use & Misuse*, 36, 1543-1570.

Guess, D., Benson, H. A., Siegel-Causey E., (1985) Concepts and issues related to choice-making and autonomy among persons with severe disabilities. *Journal-of-the-Association-for-Persons-with-Severe-Handicaps*. Vol 10(2): 79-86.

Hahn, H. (1991). Alternative views of empowerment: Social services and civil rights. *Journal of Rehabilitation*, Oct/Nov/Dec, 17-36.

Hartman, A., Laird J. (1983). Family Centered Social Work Practice (131). *The Free Press*.

Hawkins, J. D., Catalano, R. F. et al. (1992). *Community that cares: Action for drug abuse prevention*. San Francisco CA: Josey-Bass.

Hayden, M., & Abery, B. (1994). Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities. Baltimore: Paul H. Brookes.

Heinssen, R. K., Levendusky, P. G., Hunter, R. H., (1995) Client as colleague: Therapeutic contracting with the seriously mentally ill. *American-Psychologist*. 1995 Jul; Vol 50(7): 522-532.

Heinssen, R. K., Liberman, R. P.,; Kopelowicz, A. (2000) Psychosocial skills training for schizophrenia: Lessons from the laboratory. *Schizophrenia-Bulletin*.; Vol 26(1): 21-46.

Herr, S. S., (1995) Maximizing autonomy: Reforming personal support laws in Sweden and the United States. *Journal-of-the-Association-for-Persons-with-Severe-Handicaps*. Vol. 20(3): 213-223.

Herr, S. (1999) Minimizing guardianship, maximizing autonomy: Self-determination, autonomy and alternatives to guardianship. Common Sense 12/99 (6). National Program Office on Self-Determination, University of New Hampshire, Institute on Disability.

Herr, S.S., Hopkins, B. L., (1994) Health care decision making for persons with disabilities: An alternative to guardianship. *JAMA:-Journal-of-the-American-Medical-Association*. Vol. 271(13): 1017-1022.

Higgins, S.T., Budney, A. J., (1993). Treatment of Cocaine dependence through the principles of behavior analysis and behavioral pharmacology., *Behavioral Treatments for Drug Abuse and Dependence*, NIDA, pp. 97-121.

Higgins, P.C. (1992). Making a disability: Exploring the social transformation of human variation. Springfield, IL: Charles C. Thomas.

Hoffman, N. G., & Miller, N. S. (1993). Perspectives of effective treatment for alcohol and drug disorders. *Psychiatric Clinics of North America*, 16, 127-140.

Hogarty GE, Anderson CM, Reiss DJ, Kornblith SJ, Greenwald CP, Javna CD, Madonia MJ. (1986). Family psycho education, social skills training, and maintenance chemotherapy in the aftercare of schizophrenia. *Archives of General Psychiatry*, 43, 633-642.

Hoyle, D., Harris, K. (2001) Re-thinking guardianship. Center for Self-Determination (<http://www.self-determination.com/publications/printre-thinkguard.htm>).

Hughes, C., & Agran, M.(1998). Introduction to the special section: Self-determination: Signaling a systems change? *Journal of the Association for Persons with Severe Handicaps*, 20 (1), 57-65.

Hughes, C, et-al (1995) Quality of life in applied research: A review and analysis of empirical measures. *American-Journal-on-Mental-Retardation*. Vol 99(6): 623-641.

Individuals with Disabilities Education Act. (1986). IDEA. (P.L. 99457).

Jellinek, E. M. (1960). *The disease concept of alcoholism*. New Brunswick, N.J.: Hillhouse.

Joe, Simpson, Dansereau, & Rowan-Szal, 2001.

Johnson, J.R., (1999). Leadership and Self-Determination. Focus on Autism and Other Developmental Disabilities, Spring 99, Vol. 14 Issue 1, p. 4, 13 p., 2 charts.

Jones, C., Perkins, D., & Born, D. (2001). Predicting work outcomes and costs in supported employment services for persons with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 25, 53-59.

Kennedy, C.H. (2001) Social interaction interventions for youth with severe disabilities should emphasize interdependence. *Mental-Retardation-and-Developmental-Disabilities-Research-Reviews*. Vol 7(2): 122-127.

Kirby, L. D. & Fraser, M. W. (1997). Risk and resilience in childhood. In M. Fraser (ed.) *Risk and Resilience in childhood: An ecological perspective*, 10-33. Washington DC: NASW Press.

Kishi, G., Teelucksingh, B., Zollers, N., Park, L. S., Meyer, L., (1988) Daily decision-making in community residences: A social comparison of adults with and without mental retardation. *American-Journal-on-Mental-Retardation*. Vol. 92(5): 430-435.

Klein, A. R., & Cnaan, R. A. (1995). Practice with high-risk clients. *Families in Society*, 203-212.

Klingemann, H. & Sobell, L. (2001). Introduction: Natural recovery research across substance use. *Substance Use & Misuse*, 36, 1409-1416.

Kludt, C., & Perlmutter, L. (1999). Effects of control and motivation on treatment outcome. *Journal of Psychoactive Drugs*, 31, 405-414.

Kosciulek, J.E. (1999). The consumer-directed theory of empowerment. *Rehabilitation Counseling Bulletin*.

Kurzman, P. A. & Akabas, S. H. (Eds.) (1993). *Work and well being: The occupational social work advantage*. Washington DC: NASW Press.

Lam, D. H., (1991). Psychosocial family intervention in schizophrenia: A review of empirical studies. *Psychological-Medicine*. Vol 21(2): 423-441.

Latimer EA. (2001) Economic impacts of supported employment for persons with severe mental illness *Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie*. 46(6):496-505.

Latimer, W. W., Newcomb, M., Winters, K. C., & Stinchfield, R. D. (2000). Adolescent substance abuse treatment outcome: The role of substance abuse problem severity, psychosocial, and treatment factors. *Journal of Clinical and Consulting Psychology*, 68, 684-696.

Leff JP, Kuipers L, Berkowitz R, Eberlein-Vries R, Sturgeon D. (1982). A controlled study of social intervention in the families of schizophrenic patients. *British Journal of Psychiatry*, 141, 121-134.

Leff JP, Kuipers L, Berkowitz R, Sturgeon, D. (1985). A controlled trial of social intervention in the families of schizophrenic patients: two-year follow-up. *British Journal of Psychiatry*, 146, 594-600.

Leff JP, Berkowitz R, Shavit N, Strachan A, Glass I, Vaughn C. (1988). A trial of family therapy v. a relatives' group for schizophrenia. *British Journal of Psychiatry*, 153, 58-66.

Leff JP, Berkowitz R, Shavit N, Strachan A, Glass I, Vaughn C. (1990). A trial of family therapy v. a relatives' group for schizophrenia: two-year follow-up. *British Journal of Psychiatry*, 157, 571-577.

Leggett, N. M., Bates, P. (1996). Recommendations for enabling and enhancing self-determination during the transition planning process.

Lehman, A. F., & Steinwachs, D. M. (1998). Patterns of usual care for schizophrenia: Initial results from the Schizophrenia PORT client survey. *Schizophrenia Bulletin*, 24, 11-20.

Leukefeld, C. G. & Tims, F. M. (eds.) (1988). *Compulsory treatment of drug abuse: Research and clinical practice*. National Institute on Drug Abuse, Research Monograph 86.

Levene JE, Newman F, Jeffries JJ. (1989). Focal family therapy outcome study I: patient and family functioning. *Canadian Journal of Psychiatry*, 34, 641-647.

Longabaugh, R., Wirtz, P. (2001). *Project MATCH Hypotheses: Results and Causal Chain Analyses*. National Institute on Alcohol Abuse and Alcoholism, Project MATCH Monograph Series, Volume 8.

Maltzman, I. (1994). Why alcoholism is a disease. *Journal of Psychoactive Drugs*, 26, 13-31.

Maltzman, I. (1998). Reply to Lilienfeld: Why alcoholism is a disease. *Journal of Psychoactive Drugs*, 30, 99-104.

Margolis, R., Kilpatrick, A., & Mooney, B. (2000). A retrospective look at long-term adolescent recovery: Clinicians talk to researchers. *Journal of Psychoactive Drugs*, 32, 117-125.

Marinelli-Casey, P., Domier, C., & Rawson, R. (2002). The gap between research and practice in substance abuse treatment. *Psychiatric Services*, 53, 984-987.

Marlatt, G. A. (Ed.) (1998). *Harm Reduction: Pragmatic Strategies for Managing High-Risk Behaviors*. New York: The Guilford Press.

Marshall, T., Solomon, P., & Steber, S. (2001). Implementing best practice models by using a consensus-building process. *Administration and Policy in Mental Health*, 29, 105-115.

Martin, J.E., & Marshall, L.H. (1996). ChoiceMaker: Infusing self-determination instruction into the IEP and transition process. In D.J. Sands & M.L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 215-236). Baltimore: Brookes.

Matsen, A. S. (1994). Resilience in individual development: Successful adaptation despite risk and adversity. In M. Wang & E. Gordon (eds.) *Risk and resilience in inner city America: Challenges and perspectives*, 3-25. Hillsdale NJ: Earlbaum Associates.

Matsen, A. S., Hubbard, J., Gest, S. et al. (1999). Competence in the context of adversity: Pathways to resilience and maladaptation from childhood to late adolescence. *Development and Psychopathology*, 11, 143-169.

McFarlane, W. R. (1993). *Psycho educational multi-family groups: Are they a treatment of choice for schizophrenia?* Cleveland, Ohio: Center for Practice Innovations, Case Western Reserve University.

McFarlane WR, Lukens E, Link B, Dushay R, Deakins SA, Newmark M, Dunne EJ, Horen B, Toran J. (1995). Multiple-family groups and psycho education in the treatment of schizophrenia. *Archives of General Psychiatry*, 52, 679-687.

McCarty, D. & Argeriou, M. (1988). Rearrest following residential treatment for repeat offender drunken drivers. *Journal of Studies on Alcohol*, 49, 1-6.

Mechanic, D. (1991, February). Adolescent risk: New directions. Paper presented at the Annual Conference on Health Policy, Cornell University Medical College.

Mignon, S. I. (1996). Physicians' perceptions of alcoholics: The disease concept reconsidered. *Alcoholism Treatment Quarterly*, 14, 33-45.

Miller, N. S., & Flaherty, J. A. (2000). Effectiveness of coerced addiction treatment (alternative consequences): A review of the clinical research. *Journal of Substance Abuse Treatment*, 18, 9-16.

Miller, W. & Mount, K. (2001). A small study of training in motivational interviewing: Does one workshop change clinician and client behavior? *Behavioural and Cognitive Psychotherapy*, 29, 457-471.

Miller, W.R., et al. (1992). Long term follow up of behavioral self control training, *Journal of Studies on Alcohol*, 53(3) pp. 249-261.

Mead, S., Copeland, M E. (2000). *What Recovery Means to Us: Consumer's Perspectives*. *Community Mental Health Journal*, 36(3) 315-328.

Miller, D. (1999). Racial socialization and racial identity: Can they promote resiliency for African-American adolescents? *Adolescence*, 34, 493-501.

Miller D., & MacIntosh, R. (1999). Promoting resilience in urban African-American Adolescents: Racial socialization and identity as protective factors. *Social Work Research*, 23, 159-169.

Miller et al. (1992).

Mithaug, D. (1996). Equal opportunity theory. Thousand Oaks, CA: Sage.

Moos, R., & King, M. (1997). Participation in community residential treatment and substance abuse patients' outcomes at discharge. *Journal of Substance Abuse Treatment*, 14, 71-80.

Moseley, C., (1999). Making Self-Determination Work.

NAMI. (1998). *Family to Family Education Program Addition*.

National Alliance for the Mentally Ill. *Mission and History Statement* (undated). (www.nami.org/history.htm).

National Institute of Consumer-Directed Long-Term Services (1996). Principles of Consumer-Directed Home and Community-Based Services. Washington, D.C.: National Council on the Aging.

National Depressive Manic Depressive Association. *Mission Statement and Fact Sheet*. (undated). (www.ndmda.org).

Nerney, T. (2000) Challenging incompetence: the meaning of self-determination. Center for Self-Determination (<http://www.self-determination.com/publications/incompetence3print.htm>).

Nerney, T., Crowley, R. & Kappel, B. (1995). An affirmation of community: A revolution of vision and goals. Durham:University of New Hampshire, Institute on Disability.

Nerney, T., & Shumway, D. (1996). Beyond managed care: Self-determination for persons with developmental disabilities. Durham: University of New Hampshire, Institute on Disability.

Nirje, B. (1972). The right to self-determination. In W. Wolfensberger (Ed.). *Normalization* (pp. 176-193). Toronto: National Institute on Mental Retardation.

Normand, J., Lempert, R., & O'Brien, C. (eds.) (1994). *Under the influence: Drugs and the American work force*. Washington, D.C.: National Academy Press, National Academy of Sciences.

North, C. S., Pollio, D. E., Sachar, B., Hong, B., Isenberg, K., & Bufe, G. (1998). The family as caregiver for schizophrenia: A group psycho education model. *American Journal of Orthopsychiatry*, 68(1). 39-47.

O'Brien, J. (1997). Implementing self-determination initiatives: Some notes on complex change. Lithonia, GA: Responsive Systems Associates.

O'Brien, C., O'Brien, J., & Mount, B. (1997) Person-centered planning has arrived...or has it? *Mental Retardation*, 35, 480-484.

Ogborne, A., Wild, T., Braun, K., & Newton-Taylor, B. (1998). Measuring treatment process beliefs among staff of specialized addiction treatment services. *Journal of Substance Abuse Treatment*, 15, 301-312.

O'Hanlon, W. H., & Weiner-Davis, M. (1989). *In Search of Solutions: A new direction in psychotherapy*. New York: Norton.

Olney, M. F., (1999) Roles of support staff in the lives of individuals with developmental disabilities. *Journal-of-Rehabilitation-Administration*. Vol. 22(4): 249-257.

Olney, M.F., (2001). Communication Strategies of Adults with Severe Disabilities: Supporting Self-Determination. *Rehabilitation Counseling Bulletin*, Winter2001, Vol. 44 Issue 2, p. 87.

Olney, M. & Salomone, P. (1992). "Empowerment and choice in supported employment: Helping people to help themselves." *Journal of Applied Rehabilitation Counseling*, 25(3), 41-44.

Osborn, C. (1997). Does Disease Matter? Incorporating solution-focused brief therapy in alcoholism treatment. *Journal of Alcohol and Drug Education*, 43, 18-30.

Parent, W. (1993). Quality of life and consumer choice. IN E Wehman (Ed.), *The ADA mandate for social change* (pp. 19-41). Baltimore: Brookes.

Parsons, M.B. ; McCarn, J.E.; Reid, D. H. (1993) Evaluating and increasing meal-related choices throughout a service setting for people with severe disabilities. *Journal-of-the-Association-for-Persons-with-Severe-Handicaps*. Vol 18(4): 253-260.

Paulson, R., Herinckx, H., Demmler, J., Clark, G., Culter, D., Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental health service providers. *Community Mental Health Journal*, 35, 251-269.

Penn, D. L., Mueser, K. T., (1996) Research update on the psychosocial treatment of schizophrenia. *American-Journal-of-Psychiatry*. Vol 153(5): 607-617.

Polk, G. W. (1996). Treatment of problem drinking behavior using solution-focused therapy: A single subject design. *Crisis Intervention*, 3, 13-24.

Pollio, D. E., McDonald, S. M. & North, C. S. (1996). Combining strengths-based and feminist group work with the homeless. *Social Work with Groups*, 19, 5-20.

Pollio, D.E., Spitznagel, E.L., North, C.S., et al., (2000) Service Use over time and achievement of stable housing in a mentally ill homeless population. *Psychiatric Services*, Vol.51 (12): 1536-1543.

Powers, L.E., Singer, G.H.S., & Sowers, J.A. (1996). "Promoting self-competence in children and youth with disabilities." Baltimore: Brooks.

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice*, 19, 276-288.

Prochaska, J. O., & DiClemente, C. C. (1984). *The transtheoretical approach: Crossing the traditional boundaries of therapy*. Malabar, F. L: Krieger.

Prochaska, J. O., & DiClemente, C. C. (1992). Stages of change in the modification of problem behaviors. In M. Hersen, R. M. Eisler, & P. M. Miller (Eds.), *Progress in behavior modification* (Vol. 28, pp. 183-218). Sycamore, IL: Sycamore Publishing Co.

Prochaska, J. O., DiClemente, C. C., (1983) Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal-of-Consulting-and-Clinical-Psychology*. Vol 51(3): 390-395.

Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change. *American Psychologist*, 47, 1102-1114.

Prochaska, J.O., Norcross, J.C., & DiClemente, C.C. (1994). Changing for Good. New York, NY: William Morrow.

Prochaska, J. O., Velicer, W. F., Rossi, J. S., et al. (1994). Stages of change and decisional balance for twelve problem behaviors. *Health Psychology*, 13, 39-46.

Project MATCH Research Group (1997). Matching alcoholism treatments to client heterogeneity; Project MATCH post treatment drinking outcomes. *Journal of Studies on Alcohol*, 58, 7-29.

Project MATCH Research Group (1998). Matching alcoholism treatments to client heterogeneity; treatment main effects and matching effects on drinking during treatment. *Journal of Studies on Alcohol*, 59, 631-639.

Pudlinski, C., (2001). Contrary themes on three peer-run warm lines. *Psychiatric-Rehabilitation-Journal*. Vol 24(4): 397-400.

Rappaport, J. (1981). In praise of a paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology*, 9, 1-25.

Rohsenow, D. J., Niaura, R. S., Childress, A. R., Abrams, D. B., & Monti, P. M. (1990-1991). Cue reactivity in addictive behaviors: Theoretical and treatment implications. *The International Journal of the Addictions*, 25, 957-993.

Rychtarik, R., Connors, G., Whitney, R., McGillicuddy, N., Fitterling, J., & Wirtz, P. (2000). Treatment settings for persons with alcoholism: Evidence for matching clients to inpatient versus outpatient care. *Journal of Consulting and Clinical Psychology*, 68, 277-289.

Rutter, M. (1979). Protective factors in children's responses to stress and disadvantage. In M. W. Kent & J. E. Rolf (Eds.). *Primary prevention of Psychopathology*, 49-74. Hanover NH: University Press of New England.

Rutter, M. E. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57, 316-331.

Saleebey, D. (1997). *The strengths perspective in social work practice*, 2nd edition. New York: Longman Press.

Sands, D.G., Kozleski, E.B. (1994). "Quality of life difference between adults with and without disabilities." *Education and Training in Mental Retardation and Developmental Disabilities* 29, 90-101.

Sands, D.J., & Wehmeyer, M.L. (1996). *Self-determination across the life span: Independence and choice for people with disabilities*. Baltimore: Brookes.

Scala, M.A., Nerney, T. (2000) People First: The Consumers in Consumer Direction. *Generations*, Fall2000, Vol. 14 Issue 3, p55, 5p.

Schloss, P.J., Alper, S., & Jayne, D. (1994). "Self-determination for persons with disabilities: Choice, risk and dignity." *Exceptional Children*, 60, 215-225.

Schmidt, L., & Weisner, C. (1993). Developments in alcoholism treatment. In M. Galanter (Ed.), *Recent Developments in Alcoholism, Volume 11: Ten Years of Progress*, New York: Plenum Press.

Schneider, R. J., Casey, J., & Kohn, R. (2000). Motivational versus confrontational interviewing: A comparison of substance abuse assessment practices at Employee Assistance Programs. *The Journal of Behavioral Health Services & Research*, 27, 60-74.

Scotch, R.K., & Schrinier, K. (1997). Disability as human variation: Implications for policy. *Annals of the American Academy of Political and Social Science*, 549, 148-159.

Scott, J. E., & Dixon, L. B. (1995). Assertive community treatment and case management for schizophrenia. *Schizophrenia Bulletin*, 21, 657-668.

Shevin, M., & Klein, N.C. (1984). The importance of choice-making skills for students with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 9, 159-166.

Simpson, D. D. (2001). Modeling treatment process and outcomes. *Addiction*, 96, 207-211.

Simpson, D. D., & Friend, H. J. (1988). Legal status and long-term outcomes for addicts in the DARP follow-up project. *NIDA Research Monograph Series* 86, 81-98.

Smith, G. (1994). Paying for supports: Dollars, payments, and the new paradigm. In V.J. Bradley, J.A. Ashbaugh, & B.C. Blaney (Eds.), *Creating individual supports for people with developmental disabilities* (pp 481-490) Baltimore: Books.

Solomon P. (1996). Moving from psycho education to family education for families of adults with serious mental illness. *Psychiatric Services*, 47, 1364-1370.

Solomon P, Draine J, Mannion E, et al. (1996). The impact of individualized consultation and group workshop family education interventions on ill relative outcomes. *Journal of Nervous and Mental Disease*, 184. 252-254.

Solomon P, Draine J, Mannion E, & Meisel M. (1997). Effectiveness of two models of brief family education: Retention of gains by family members of adults with serious mental illness. *American Journal of Orthopsychiatry*, 67, 177-186.

Sowers, J.A. Powers, L., (1995) Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities. *Mental-Retardation*. Vol 33(4): 209-220.

Spaniol, L. (1999). Implications of Recovering for Mental Health Systems and Programs., Eric Document 435900.

Spaniol, L., Gagne, C., & Koehler, M. (1998). *Psychological and Social Aspects of Psychiatric Disability* (Teaching/Training Guidelines). Boston, MA: Boston University, Center for Psychiatric Rehabilitation.

Stalker, K., & Harris, P. (1998). The exercise of choice by adults with intellectual disabilities: A literature review. *Journal of Applied Research in Intellectual Disabilities*, 11, 60-76.

Stancliffe, R.J.,(1997) Community living-unit size, staff presence, and residents' choice-making. *Mental-Retardation*. 1997 Feb; Vol 35(1): 1-9.

Stancliffe, R.J., Abery, B. H., (1997) Longitudinal study of deinstitutionalization and the exercise of choice. *Mental-Retardation*. 1997 Jun; Vol 35(3): 159-169.

Stancliffe, R. J, et al., (2000) Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal-of-Intellectual-and-Developmental-Disability*. 2000 Dec; Vol 25(4): 281-305.

Stancliffe, R. J., Parmenter, T.R., (1999) The Choice Questionnaire: A scale to assess choices exercised by adults with intellectual disability. *Journal-of-Intellectual-and-Developmental-Disability*. 1999 Jun; Vol 24(2): 107-132.

Stancliffe, R., & Wehmeyer, M.L. (1995). Variability in the availability of choice to adults with mental retardation. *Journal of Vocational Rehabilitation*, 5, 319-328.

Substance Abuse and Mental Health Services Administration (2000, November). *Changing the Conversation*.

Swanson, A. J., Pantaloni, M. V., & Cohen, K. R. (1999). Motivational interviewing and treatment adherence among psychiatric and dually diagnosed patients. *The Journal of Nervous and Mental Disease*, 187, 630-635.

Szymanski, E.M., & Trueba, H.T. (1994). Castification of people with disabilities: Potential disempowering aspects of classification of disability services. *Journal of Rehabilitation*, 60 (3), 12-20.

Tarrier N, Barrowclough C, Vaughn C, Bamrah JS, Porceddu K, Watts S, Freeman H. (1989). The community management of schizophrenia: a controlled trial of a behavioral intervention with families to reduce relapse. *British Journal of Psychiatry*, 153, 532-542.

Tarrier N, Barrowclough C, Vaughn C, Bamrah JS, Porceddu K, Watts S, Freeman H. (1989). Community management of schizophrenia: a two-year follow-up of a behavioral intervention with families. *British Journal of Psychiatry*, 154, 625-628.

Taylor, S. J., Biklen, D., & Knoll, J. (1989). Community integration for people with severe disabilities. New York: Teachers College Press.

The American Heritage Dictionary of the English Language, Third edition (1992). Houghton Mifflin Company.

Timko, C., & Moos, R. (1998). Determinants of the treatment climate in psychiatric and substance abuse programs: Implications for improving patient outcomes. *Journal of Nervous and Mental Disease*, 186, 96-103.

Tims, F. M. & Leukefeld, C. G. (eds.) (1986). Relapse and recovery in drug abuse. National Institute on Drug Abuse, Research Monograph, 72.

Tossebro, J., (1995) "Impact of size revisited: Relation of number of residents to self-determination and deprivatization": Erratum. *American-Journal-on-Mental-Retardation*. Vol 100(3): 243.

Vaillant, G. (1993). *The wisdom of the ego: Sources of resilience in adult life*. Cambridge MA: Harvard University Press.

Van Horn, D., & Bux, D. (2001). A pilot test of motivational interviewing groups for dually diagnosed inpatients. *Journal of Substance Abuse Treatment*, 20, 191-195.

Waller, M. A. (2001). Resilience in ecosystemic context: Evolution of the concept. *American Journal of Orthopsychiatry*, 71, 290-297.

Walsh, F. (1998). *Strengthening family resilience*. New York: Guilford Press.

Ward, M. J. (1988). The many faces of self-determination. *National Information Center for Children and Youth with Handicaps Transition Summary*, 5, 2-3.

Ward, M.J., & Halloran, W.D. (1993). Transition Issues for the 1990's OSERS News in Print, VI(1), 4-5.

Ward, M.J., & Kohler, P.D. (1996). Promoting self-determination for individuals with disabilities: Content and process. In L.E. Powers, G.H.S. Singer, & J. Sowers (Eds.), *Making our way: Building self-competence among children with disabilities*. Baltimore, MD: Brookes.

Wehmeyer, M. L. (1996) Self-Determination as an educational outcome, in *Self-Determination Across the Life Span*, D. J. Sands, & M. L. Wehmeyer (Eds). Baltimore, MD: Paul H. Brooks Publishing Co. 17 – 36.

Wehmeyer, M. L., (1996) Student self-report measure of self-determination for students with cognitive disabilities. *Education-and-Training-in-Mental-Retardation-and-Developmental-Disabilities*. Vol. 31(4): 282-293.

Wehmeyer, M. L., Kelchner, K., Richards, S., (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American-Journal-on-Mental-Retardation*. Vol 100(6): 632-642.

Wehmeyer, M. L., Sands, D. J., et al.,(1997). The development of self-determination and implications for educational interventions with students with disabilities. *International-Journal-of-Disability,-Development-and-Education*. Vol. 44(4): 305-328.

Wehmeyer, M. L., Schwartz, M. (1998). The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 3-12

Wehmeyer, M.L. (1992a). "Self-determination and the education of students with mental retardation." *Education and Training in Mental Retardation*, 27(4), 302-314.

Wehmeyer, M.L. (1994). "Self-determination as an educational outcome." *TASH Newsletter*, 20 (4), 16-17, 26.

Wehmeyer, M.L., & Metzler, C.A. (1995). How self-determined are people with mental retardation? The National Consumer Survey. *Mental Retardation*, 33, 111-119.

Wehmeyer, M.L., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities: Basic skills for successful transition*. Baltimore: Books.

Wehmeyer, M.L., Kelcher, K., & Richards, S. (1995). Individual and environmental factors related to the self-determination of adults with mental retardation. *Journal of Vocational Rehabilitation*, 5, 291-305.

West, M., Kregal, J., & Revell, G. (1994). A new era of self-determination. *TASH Newsletter*, 20 (7), 11-12.

West, M.D., & Parent, W.S. (1992). Consumer choice and empowerment in supported employment services: Issues and strategies. *Journal of the Association for Persons with Severe Handicaps*, 17 (1), 47-52.

White, W. (April 3-5, 2000). Toward a New Recovery Movement: Historical Reflections on Recovery, Treatment and Advocacy., Recovery Community Support Program Conference, Working Together for Recovery? Alexandria, Virginia.

White, M. & Epston, D. (1989). *Literate means to therapeutic ends*. Adelaide, Australia: Dulwich Publications.

Williams, R. (1991). Choices, communication and control: A call for expanding them in the lives of people with disabilities. In L.H. Meyer, C.A. Peck, & L. Brown (Eds.), *Critical issues in the lives of people with disabilities* (pp. 543-544). Baltimore: Brookes.

Wolf-Branigin, M., & Sawilowsky, S. (1994). Perceived importance of self-determination factors by consumers in substance-abuse treatment. *Perceptual and Motor Skills*, 79, 284-286.

Wolin, S., Wolin, S. J., (1996). The challenge model: Working with strengths in children of substance-abusing parents. *Child-and-Adolescent-Psychiatric-Clinics-of-North-America*. Vol. 5(1): 243-256.

Wolin, S. & Wolin, S. (1993). *The resilient self: How survivors of troubled families rise above adversity*. New York: Villard Books.

Yanos, P., Primavera L., Knight E. *Consumer-Run Service Participation, Recovery of Social Functioning, and the Mediating Role of Psychological Factors*. Psychiatric Services. (2001) 52(4) 493-500.

Young, S., Ensing, D. *Exploring Recovery From the Perspective of People with Psychiatric Disabilities*. Psychiatric Rehabilitation Journal. (1999) 22(3) 219-231.

Yoder, S. (2002, March-April). Individual responsibility for health: Decision, not discovery. *Hastings Center Report*, 32, 22-31.

Yuskauskas, A., Conroy, J., & Elks, M. (1997). Live free or die: A qualitative analysis of systems change in the Monadnock Self Determination Project. Concord: University of New Hampshire, The Center for Outcome Analysis.

Ziedonis, D., George T. (1997). Schizophrenia and nicotine use – report of a pilot smoking cessation program and review of neurobiological and clinical issues. Schizophrenia Bulletin, 23, 247-254.

Zimmerman, M.A. (1990). Taking aim on empowerment research: On the distinction between psychological and individual conceptions. *American Journal of Community Psychology*, 18, 169-177.